SURGICAL CANCER PATIENTS' PREFERENCES FOR INFORMATION AND DECISION MAKING CONTROL

BY

DEANNE RHONDA SPIEGEL

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

MASTER OF NURSING

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University of Manitoba
Winnipeg, Manitoba

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Modern	0298
African	0316
American	0591
Asian	0305
Canadian (English)	0352
Canadian (French)	0355
English	0593
Germanic	0311
Latin American	0312
Middle Eastern	0315
Romance	0313
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Religion	
General	0318
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Labor	0510
Theory	0511
Folklore	0358
Geography	0366
Gerontology	0351
History	
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	0333
United States	0337
History of Science	0585
Law	0398
Political Science	
General	0615
International Law and Relations	0616
Public Administration	0617
Recreation	0814
Social Work	0452
Sociology	
General	0626
Criminology and Penology	0627
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Social Structure and Development	0700
Theory and Methods	0344
Transportation	0709
Urban and Regional Planning	0999
Women's Studies	0453

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Forestry and Wildlife	0478
Plant Culture	0479
Plant Pathology	0480
Plant Physiology	0817
Range Management	0777
Wood Technology	0746
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General	0306
Anatomy	0287
Biostatistics	0308
Botany	0309
Cell	0379
Ecology	0329
Entomology	0353
Genetics	0369
Limnology	0793
Microbiology	0410
Molecular	0307
Neuroscience	0317
Oceanography	0416
Physiology	0433
Radiation	0821
Veterinary Science	0778
Zoology	0472
Biophysics	
General	0786
Medical	0760

EARTH SCIENCES

Biogeochemistry	0425
Geochemistry	0996
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	
General	0566
Audiology	0300
Chemotherapy	0992
Dentistry	0567
Education	0350
Hospital Management	0769
Human Development	0758
Immunology	0982
Medicine and Surgery	0564
Mental Health	0347
Nursing	0569
Nutrition	0570
Obstetrics and Gynecology	0380
Occupational Health and Therapy	0354
Ophthalmology	0381
Pathology	0571
Pharmacology	0419
Pharmacy	0572
Physical Therapy	0382
Public Health	0573
Radiology	0574
Recreation	0575
Speech Pathology	0460
Toxicology	0383
Home Economics	0386

PHYSICAL SCIENCES

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

Applied Sciences

Applied Mechanics	0346
Computer Science	0984
Engineering	
General	0537
Aerospace	0538
Agricultural	0539
Automotive	0540
Biomedical	0541
Chemical	0542
Civil	0543
Electronics and Electrical	0544
Heat and Thermodynamics	0348
Hydraulic	0545
Industrial	0546
Marine	0547
Materials Science	0794
Mechanical	0548
Metallurgy	0743
Mining	0551
Nuclear	0552
Packaging	0549
Petroleum	0765
Sanitary and Municipal	0554
System Science	0790
Geotechnology	0428
Operations Research	0796
Plastics Technology	0795
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

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TABLE OF CONTENTS

ABSTRACT

This descriptive study investigated preferred and assumed surgical treatment decision making roles, preferred and assumed postoperative care decision making roles, rank order of preferences regarding participation in nine postoperative care decisions, and pre-discharge information needs in 51 hospitalized postoperative cancer patients who were within three days of discharge. The Control Preference Card Sort was used to determine that most patients preferred passive surgical decision making roles. Thurstone's Law of Comparative Judgement was used to determine that the most preferred postoperative care decision in which to participate, irrespective of age, gender, education, coexisting illness, place of residence, beliefs about surgical outcome, and decision role category preferences and perceptions was "activities to do and avoid doing at home." Because postoperative care decisions that patients chose as most preferred for decisional participation had not been confirmed clinically with 20 patients, cell sizes were insufficient to determine statistical significance of the differences between preferred and assumed postoperative care decisions and between assumed postoperative care and surgical treatment decisions. When decision making roles were collapsed to active/collaborative and passive, Chi square tests indicated that preferred surgical decision roles and preferred postoperative care decision roles were not significantly different but preferred and assumed surgical decision making roles were divergent (p=0.001). Those who preferred active/collaborative roles assumed their preferred roles less frequently than patients who preferred passive roles. Patients who were older, male, less educated, had coexisting illnesses, resided in Winnipeg, and believed they were cured were preferred to leave all treatment decisions to the physician. Patients who were younger, female, more educated, did not have coexisting illness, did not reside in Winnipeg, and were unsure if they were cured preferred the physician to make the final decision about which treatment to use, but seriously consider the patient's opinion. Patients who assumed active/collaborative decision making roles identified a greater need for pre-discharge information than those who assumed passive roles (p=0.0238). The results of this study highlight the need to assess patients' preferred decision making roles.

DEDICATION

This thesis is dedicated to the memory of my parents, Sylvia and Edward Caplan

and

To my family and friends who supported me and urged me to persevere.

ACKNOWLEDGEMENTS

I am grateful to the members of my thesis committee who guided me through the process of research and thesis writing. Dr. Lesley Degner, the chair of my committee, shared her expertise and insights with me. Dr. David Gregory helped me to believe in myself and stimulated my motivation to continue when it was most needed. Dr. Barry Anderson helped me consider the clinical applications of my research through the questions he posed.

Several other people facilitated the implementation and completion of this work. Dr. Jeff Sloan provided guidance on working with the SAS program on the mainframe and spent time with me in confirming my interpretations of the statistics that were generated. My son, Gary Spiegel retrieved my thesis from the computer after I accidentally deleted it. My daughter and son-in-law, Jill and Lorrie Kirshenbaum helped me obtain articles, produced my slides and provided computer assistance.

Thank you to my husband who lived the experience of obtaining a masters degree with me. He never lost faith that completion was possible when my spirit waned.

LIST OF FIGURES

LIST OF TABLES

CHAPTER 1

INTRODUCTION

Statement of the Problem

Patients are expected to have faith in and to obey their physicians (Mark & Spiro, 1990) without seeking justification of physicians' decisions (Fisher, 1988; Freidson, 1986). Good patients conform to these expectations by giving up the adult role during patient-physician encounters (Sharf, 1988). This traditional relationship was described by Szasz and Hollender (1956) as the authoritative-guidance model. Because of the significant potential for patient exploitation in the authoritative-guidance relationship, the President's Commission for the Study of Ethical Problems (1982) concluded that decisions made under these circumstances may be questioned. The power imbalance in authoritative-guidance relationships diminishes the possibility for patients to become aware of treatment alternatives and to negotiate a more active role (Roter, 1987).

Physicians have been a dominant, autonomous and authoritative influence in modern health care (Charles & DeMaio, 1993; Freidson, 1986). Their influence was gained through professionalization, passage of laws which eliminated competition from others, and a popular belief that medical knowledge has resulted in a dramatic improvement in the cure of diseases (Conrad & Schneider, 1986). Physicians assumed responsibility for treatment decision making supposing that patients were not capable of comprehending health and alternative treatment information in a rational and responsible manner and that such information would be harmful to them. (Freidson, 1986; Kaplan, 1991; Lantos, 1993). However, Hearn (1992) pointed out that the exercise of therapeutic privilege, the allowance of a physician to make a therapeutic decision for the patient without consulting the patient, should only be used in exceptional circumstances.

In the 1970's in the United States, an attitude of patient consumerism in health care emerged (Harris, Boyle & Brounstein, 1982; Haug, 1976; Haug & Lavin, 1979, 1981, 1983; Henry, 1993; Kaplan, 1991; Kasteler, Kane, Olsen & Thetford, 1976, Reiser, 1993). It was believed that patients were wanting greater control in decisions affecting their own health (Roter, Hall & Katz, 1988). In an annotated bibliography pertinent to cancer patients' communication with health care professionals, Degner, Farber and Hack (1989) concluded that:

- A majority of patients prefer to share treatment control with their physicians, as opposed to a) letting the physicians formulate all of the decisions, or b) developing a treatment strategy themselves.
- Younger patients prefer more active involvement than

> older patients (p. 56).

The authors also concluded that females, single persons, and the well-educated prefer an active role in treatment decision making, and that physicians may overestimate the level of participation in decision making that their patients prefer. A recent survey of cancer patients in Manitoba revealed that the majority preferred a passive role in treatment decision making, while the majority of the public, should they contract cancer, preferred an active role (Degner & Sloan, 1992).

To participate knowledgeably in treatment decision making, the patient requires information about the disease and its progress, the various treatment alternatives available and the probable consequences related to each of the alternatives. For those patients who wish to share responsibility for resolving their health concerns, participating in decision making may combat feelings of helplessness brought on by the diagnosis of cancer and being hospitalized (Northouse & Wortman, 1990). Information seeking has been posited as the primary mode for coping with novel, ambiguous, or unfamiliar situations (Lazarus, 1966). From the majority of studies related to cancer patients' preferences for information needs, Degner et al. (1989) concluded that:

- Cancer patients are dissatisfied with the kind and/or amount of medical information they receive from physicians and nurses.

- Physicians and, to some extent, nurses underestimate the amount and misperceive the type of information that patients desire (p. 5).

Although patients usually want maximal information (Beisecker, 1988; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Brandt, 1991; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Haug, 1976; Haug, 1979; Haug & Lavin, 1978, 1979; Rothert, 1991; Silverstein et al. 1991), they make few attempts to seek it from health professionals (Avis, 1994; Grahn & Johnson, 1990; Karini & Wiltshaw, 1986; Meyerowitz, 1993) unless they are given sufficient time (Beisecker & Beisecker, 1990) or feel confident that they can handle their health care problems (Barsevick & Johnson, 1990; Johnson, Christman & Stitt, 1985). Although patients have indicated that they want to participate in treatment decision making (Degner et al, 1989), several studies (Beisecker & Beisecker, 1990; Beisecker, Helmig, Graham, & Moore, 1994; Degner & Sloan, 1992; Ende, Kazis, Ash & Moskowitz, 1989; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler & Till, 1989; Waterworth & Luker, 1989) have indicated that most patients believe physicians should assume most of the responsibility for medical decision making. Patients expressed more desire for participation in treatment decision making when considering important options that they felt qualified to evaluate (Biley, 1992; Thompson, Pitts, & Schwankovsky, 1993), if they felt well enough, and if they were not subject to organizational constraints preventing their participation (Biley, 1992).

When actual decision making was examined, researchers found that most patients assume a passive role (Degner & Beaton, 1987; Lidz & Meisel, 1982; Strull, Lo & Charles, 1984; Sutherland et al., 1989; Brooking, 1989). Difficulty in obtaining information and maintaining a sense of control has been an issue for cancer patients (Northouse & Northouse, 1987). Problems with patient-provider communication has put patients at a disadvantage in gaining and comprehending information they require to make treatment decisions (Blum & Blum, 1991).

Vachon, Lancee, Conway and Adair (1990) found that 84% of Manitobans with cancer had been able to ask questions and obtain the information they wanted from their physicians. However, only 42% to 55% had spoken to health care providers other than physicians and were satisfied with the information they were able to obtain. Frank and open discussions about the disease took place in only 54% of the cases with physicians and in only 29% of the cases with other health care professionals. The researchers found that the times of diagnosis and surgery were among Manitoba cancer patients' worst times for major problems. Patients perceived that their major problems went unresolved 41% of the time. Major problems that went unresolved included dealing with the side effects of the disease and its treatment and with the aftermath of surgical procedures. Only 5% of the respondents turned to health professionals other than physicians for help. Unmet needs were associated with high distress and low quality of life. The researchers suggested that more patients' problems could be resolved if communication with health care professions other than physicians were increased. These finding indicate that excessive numbers of cancer patients' needs were not being met at a satisfactory level when they were informed of their diagnosis and when they were recovering from their surgical treatment. Since only 54% had frank discussions with their physicians and only 29% with other health professionals, perhaps emotional support and information was not as easily available to Manitoba cancer patients as was required for them to cope with their diagnosis and its treatment and to implement effective coping strategies after surgery. Lack of information could have also interfered with active involvement in treatment decision making with their physicians.

To cope with the stress of having cancer and to be able to engage in treatment decision making, patients require emotional support and factual information about immediate and long term physical and psychological implications of their illness and treatment (Leinster, 1994). Patients' adjustment to stress is facilitated by their obtaining information about the nature of the disease, the medical reasons for initiating particular treatments, the medical procedures to be carried out, the expected sensations and side effects, and strategies to cope with threats (Cohen & Lazarus, 1979). Cohen and Lazarus (1979) suggested that providing this type of information to patients may help them maintain some control which in turn may facilitate adjustment to stressful situations. Better emotional outcomes tend to occur when adequate information is provided (Meyerowitz, 1993). Unfortunately, many cancer patients have knowledge deficits about their disease, treatments, (Grahn & Johnson, 1990; Mackillop, Stewart, Ginsburg, & Stewart, 1988; Sutherland, Lockwood, & Till, 1990) and diagnostic tests (Nugent & Tamlyn-Leaman, 1992).

There is some evidence that patient participation in treatment decision making has positive outcomes. Breast cancer patients who were offered a choice between mastectomy or lumpectomy adjusted better with regard to resuming work, attitude about the future, coping beliefs, and physical and psychological functioning (Morris & Ingham, 1988), and they experienced less depression and anxiety (Fallowfield, Hall, Maguire, & Baum, 1990; Morris & Royle, 1988) than those who were not offered a choice. Ninety-three percent of Stage D prostate cancer patients who chose either orchiectomy or hormonal therapy were satisfied with their treatment choice after three months had passed (Cassileth et al., 1989).

Nurses claim to be patient advocates (Canadian Nurses Association, 1991). As such they should assist patients to obtain the information they feel is needed and to achieve their preferred level of control in treatment decision making. In a study identifying dimensions of client control, Dennis (1987) concluded that "nurses have a central role in identifying patients who want to be involved in making decisions about their care and in providing support for that active involvement" (p. 155). She noted that cancer patients were highly represented in the group of patients who preferred to have an active decision making role. Nurses should enter into transactions with patients' families and other members of the health care team to negotiate for maximization of the patient's freedom of choice (Benoliel, 1986) and should negotiate transactions with patients to facilitate achievement of the patient's goals (King, 1981).

If patients want to assume reasoned collaborative or independent roles in treatment decision making, they need to comprehend specific information. To achieve this end, improvement in educational and emotional support may be indicated. Providing information and facilitating participation in treatment decision making at cancer patients' preferred level may help them cope with the diagnosis and the aftermath of surgery. To help care givers provide the information and emotional support needed by postoperative cancer patients, care givers need to know (a) in which postoperative care decisions patients believe are important for them to participate, (b) patients' treatment decision role preferences and (c) care giver behaviours that enable or hinder patient attainment of information and preferred treatment decision making roles.

Purpose of the Study

Although previous studies have been carried out regarding patients' preferences for information and decision making control, there has been a dearth of studies which evaluate postoperative cancer patients' opinions about the relative importance of participating in specific postoperative care decisions. The main goals of this study were:

1. To pilot test a method of determining patients' priorities for participation in postoperative care decisions.
2. To determine if preferred and actual decision making roles in deciding on the surgery differed from preferred and actual decision making roles for postoperative care.
3. To determine if patients' perceptions of the information they need upon discharge from hospital is associated with their perceived roles in treatment decision making.

This descriptive study was built on research by Degner and Russell (1988) and Degner and Sloan (1992) concerning adult cancer patients' preferences for control in medical treatment decision making and extended it to postoperative care decisions of the surgical cancer patient. The specific objectives of the study were: (a) to rank, from the patient's perspective, the order of importance of participating in nine postoperative care decisions, (b) to determine if patients prefer the same role in deciding to have surgery as they do in making the postoperative care decisions, (c) to determine if there is congruence between patients' preferred and actual decision making roles, (d) to determine the relationship among patients' perceived information needs, preferred and actual decision making roles, and beliefs about the effect of surgery on curing the illness, and (e) to explore patients' perceptions of the effects of nursing behaviors on attainment of information needs and preferred decision making roles.

Assumptions

In this study, it is assumed that (a) patients prefer to have more involvement with some postoperative care decisions than with other postoperative care decisions and (b) patients are capable of selecting the postoperative care decisions that they feel are most important in which to have a say.

Significance of the Study

Guse and Degner (1990) clarified the difference between the role of nurses as advocates and as social agents. They explained the role of nurses as advocates who act at the level of individual and family care and of nurses as social agents who stimulate, develop and participate in social change. This study explored if and how nurses are perceived by patients as advocates in helping them achieve their preferred decision making roles. The results of this study may facilitate a small step toward social change to increase nurse and physician support of patient-provider partnership in health care decision making. This study also revealed information that nurses can use to help patients assume their preferred decision making roles.

The results of this pilot study could form the basis for further investigation (a) to identify specific health care decisions in which patients want input, (b) to determine if there are differences in outcomes among patients who prefer active, collaborative and passive decision making roles and (c) to determine differences in outcomes associated with patients who assume and who do not assume their preferred decision making roles. A better understanding of postoperative cancer patients' perceptions about discharge information needs and their views about barriers and aids in assuming their preferred decision making roles may help nurses and physicians meet patients' needs in an effective manner at a time of emotional stress. More effective interventions by nurses as advocates to support cancer patients' preferred decision making role may increase their ability to cope with the continuing uncertainty of their illness and its treatment.

Cancer patients have many problems. Obstacles that prevent assumption of the decision making roles cancer patients prefer could be interfering with their ability to cope with the cancer experience. This study could provide guidance to practitioners in helping patients more easily assume a partnership role in treatment decision making when that role is preferred.

Conceptual Framework

The conceptual framework for this study was based on Brickman and colleagues' (1982) models of helping and coping. Roter's (1987) models of client-provider relations and Wilson's (1983) conceptualization of cognitive authority were also used to provide theoretical links that are needed for a more comprehensive conceptualization of preferred and actual decision making roles.

Models of Helping and Coping

Brickman et al.'s (1982) four models of helping and coping consider the perspective of both the helper and the person being helped when resolving problems. The models - moral, enlightenment, medical, and compensatory - differ from each other according to the amount of responsibility people assign to themselves for causing and resolving their own health problems. The beliefs of people who ascribe to the four different models of helping and coping are listed in Table 1.

Brickman et al.'s (1982) models of helping and coping were chosen because patients' preferences for participation in treatment decision making are expected to conform to their self-attributes of responsibility for resolving health problems. Patients who prefer to take a passive role and let the health care provider make treatment decisions abrogate responsibility for resolving health problems. Patients who believe they are responsible for solving their health problems are expected to take an active or collaborative role health care decision making.

This study is concerned with helping cancer patients who are in a setting where the medical model and the compensatory model are fundamental to the practice of medicine and nursing. These professions do not consider holding patients solely responsible for causing their cancer as acceptable. Therefore the medical model and the compensatory model are primarily used in this study. However, because patients may be classified into any of the four models of helping and coping, all four will be described to acquaint the reader with the entire framework.

Table 1. *Consequences of attribution of responsibility for the problem and for its solution in four models of helping and coping.* From, "Models of helping and coping," by P. Brickman, V. C. Rabinowitz, J. Karuza Jr., D. Coates, E. Cohn, and L. Kidder, 1982, *American Psychologist, 37,* p. 370.

	Attribution to self of responsibility for solution	
Attribution to self of responsibility for problem	High	Low
High	MORAL MODEL	ENLIGHTENMENT MODEL
Perception of self	lazy	guilty
Actions expected of self	striving	submissive
Others who must act	peers	authorities
Actions expected of others	extortion	discipline
Implicit view of human nature	strong	bad
Potential pathology	loneliness	fanaticism
Low	COMPENSATORY MODEL	MEDICAL MODEL
Perceptions of self	deprived	ill
Actions expected of self	assertion	acceptance
Others who must act	subordinates	experts
Actions expected of others	mobilization	treatment
Implicit view of human nature	good	weak
Potential pathology	alienation	dependency

Brief examples from Northouse and Wortman's (1990) theoretical analysis of the four models as they relate to cancer care follow.

Moral Model

In the moral model, people assume high responsibility for both causing and resolving health problems. Followers of the self-help movement and psychosomatic theorists conform to this model. An example of people ascribing to the moral model is a belief that inability to cope with life stresses is a cause of cancer. Although there is no obligation for others to help, helpers may encourage clients to change and remind them of their roles in causing and curing cancer. People with cancer might use psychological interventions such as using imagery to try to activate the body's immune system to fight off the cancer cells or expressing their anger and despair to reduce their stress. Although these types of interventions have demonstrated a positive effect in increasing patients' perceived control over the disease and have increased their ability to cope psychologically with the disease, they are not accepted by medical science as primary cancer treatments. There is a danger that cancer patients may be encouraged to assume control over the disease when control is not possible and a possibility of increased emotional stress if the intervention fails. Although Cassileth, Lusk, Miller, Brown and Miller (1985) found no evidence that psychosocial and life-style factors have altered the progress of the disease in patients with advanced malignancies, Spiegel, Bloom, Kraemer and Gottheil (1989) observed that certain emotional states do lead to both improved quality of life and greater longevity for cancer patients.

Concerns arise when responsibility for causing the illness is borne by the patient. Blaming one's self for having caused one's cancer may lead a person to believe that the illness is deserved because of some character defect. When patients are blamed for having developed the disease, victimization and self-blame may be fostered. Self-blame has been associated with low self-esteem, feelings of helplessness (Northouse & Wortman, 1990), and a belief that surgery would be unsuccessful in removing the cancer (Timko & Janoff-Bulman, 1985). Although some lifestyle factors have been implicated in the development of some types of cancer, the cause of cancer remains unknown. Blaming the victim adds more stress to already stressful situation.

Enlightenment Model

People ascribing to the enlightenment model attribute high responsibility to themselves for causing their health problems but low responsibility for resolving them. Folk medicine and spiritual healing are consistent with this model. Healers in this model appeal to cancer patients because they deal with the patients' existential concerns, help patients understand the meaning of their suffering, and offer love and hope for a cure. Cancer patients, who believe that their unacceptable behaviour caused their disease and who feel they must submit to themselves to the will of a higher authority, are examples of patients and who have adopted the enlightenment model. The cancer patient is encouraged to confess shortcomings and is given ongoing social support at weekly group meetings. Supporters of this model attempt to "enlighten" others by disseminating their beliefs and by encouraging use of their methods. Participation in support groups fosters communication, sharing and advocacy (Monaco, 1992). Research has shown that support groups have been effective in improving mood, adjustment, pain and survival rates (Spiegel et al., 1989). The fear is that cancer patients may abandon conventional medical therapy in favour of healing groups and "natural" therapies. Blaming the cancer patient for having caused the illness is fraught with that same psychological hazards that were discussed in the moral model.

Medical Model

In the medical model, patients assume low responsibility for both causing and resolving their health problems. The cause of people's problems are viewed as being subjected to forces beyond their control. This model embodies many of the assumptions that have been predominant in the traditional practice of medicine. Patients are expected to accept their state of illness, and to seek and utilize expert help. Responsibility for the diagnosis, treatment decisions and evaluation of outcomes is borne entirely by the health care provider. Patients delegate medical decision making control to the health care professional; practitioners have a paternalistic orientation toward patient care. When cancer patients are overwhelmed with feelings of helplessness, the medical model frees them from the burden of deciphering confusing information and from taking responsibility for treatment decisions (Northouse & Wortman, 1990). Patients are not blamed for causing their cancer. They may be comforted in believing that all-knowing all-powerful health professionals (Brody, 1980) will take care of them.

Northouse and Wortman (1990) pointed out three limitations of the medical model. (1) It does not recognize patients' ability to marshall their own strengths to cope with illness. This may limit patients' potential to recognize their own strengths in being able to cope and could foster continuing dependence on the health care provider. (2) It promotes a power imbalance of the patient-practitioner relationship. A consequence of this situation may result in health care decisions being made on the basis of the practitioner's values rather than the patient's values (Kassirer, 1994). (3) A tremendous burden is placed on the health professional who must confront an illness that is uncontrollable and life-threatening. Treatment failures are attributed to the practitioner, not the patient.

Compensatory Model

People in the compensatory model attribute low responsibility to the patient for causing the health problem but high responsibility for resolving it. Patients adopting this model compensate for problems that their illness has imposed upon them by using their own efforts or by collaborating with others. The helper's role is to provide the opportunities or resources that the patient needs to resolve the problem. Helpers provide education which empowers patients to deal more effectively with their concerns. Patients, in trying to solve their problems act assertively to obtain the resources they need. When the goals and values of the patient are incorporated into the treatment plan, patients determine or have a share in determining which resources to use and whether the help was successful.

Nursing interventions, such as teaching and counseling, that help patients attain and regain self care are examples of how nurses work within the compensatory model. Cancer education programs and peer support groups have utilized the compensatory model by providing patients with information, resources and opportunities they need to compensate for the limitations imposed by their illness (Northouse & Wortman, 1990). Providing patients with the information they feel they need and giving them the opportunity to participate in treatment decision making are examples of health care interventions using the compensatory model. Patients who prefer to keep decision making control or share it with the health care provider fit into the compensatory model.

Northouse and Wortman (1990) identified four strengths of the compensatory model. (1) Independence from health care professionals for minor decisions is gained through educational programs that increase patients' sense of control. (2) Active participation in treatment decision making is associated with positive health outcomes (Cassileth et al, 1989; Fallowfield et al., 1990; Morris & Ingham, 1988; Morris & Royle, 1988). (3) The human potential to confront and overcome life stresses is recognized. (4) Patients are not blamed for causing their cancer.

Application of the compensatory model to all patients was the only limitation identified by Northouse and Wortman (1990). Patients who do not want to be informed or who prefer to take a passive role in treatment decision making may receive unwanted information or feel compelled to assume a role that they do not want or feel equipped to handle (Waterworth & Luker, 1989). This may put cancer patients who are feeling stressed because of their health status into an even more stressful situation. Assessing preferences for information and decision making control is therefore important before using the compensatory model.

Cognitive Authority

Although some patients prefer to take an active or collaborative role in treatment decision making, it is not always achieved (Kohler, 1988). Wilson's (1983) conceptualization of cognitive authority was chosen because it provides a partial explanation why patients sometimes have less control over treatment decision making than they prefer.

Assumption of collaborative or active decision making requires achievement of cognitive authority. Cognitive authority is achieved rather than given. According to Wilson (1983), to have cognitive authority one's knowledge must be respected by another to such an extent that it will influence the other's thinking. Person A becomes an authority for Person B, with respect to a certain field of interest, if what A says about the subject is respected and matters to B (Wilson, 1983, p. 13). Physicians are recognized as cognitive authorities concerning medical treatment because society in general, and the patient in particular, respect and are influenced by physicians' knowledge and opinions.

As a person gains more knowledge in a certain field of interest more cognitive authority is gained (Wilson, 1983). When this statement by Wilson is applied to a patient and a physician, the following conclusions might be drawn. (1) As the patient's knowledge about his or her illness increases, the patient's cognitive authority increases. (2) As the difference between the physician's knowledge and the patient's knowledge about patient's illness and treatment is narrowed the degree of cognitive authority that the physician has over the patient decreases.

Unfortunately, the style in which many physicians provide their patients with information has made it difficult for patients to acquire information (Miyaji, 1993; Taylor, 1988) and, after having received information, patients have demonstrated poor recall, comprehension and application (Blum & Blum, 1991; Hughes, 1993; Mackillop et al., 1988; Sutherland et al., 1990). The following explanations for these results have been offered. (1) Patients misinterpreted words and phrases on consent forms (Sutherland et al.,1990). (2) Patients give more weight to prior information from friends, family and media than from the physician when selecting either lumpectomy or mastectomy (Hughes, 1993). (3) Patients have a great deal of anxiety when information is presented (Blum & Blum, 1991; Hughes, 1993). (4) An overly optimistic approach in presenting information or the patient's use of denial may have caused misunderstandings (Mackillop et al., 1988). (5) Patient education may not have been provided at an acceptable standard (Redman, 1993). Because cancer patients appear to be having difficulty in understanding and using information received from health professionals, it would appear that the medical knowledge gap between patient and physician is not usually narrowed very much. Doctors retain their status as cognitive authorities about medical information.

However, people are cognitive authorities in the sphere of their own personal experience (Wilson, 1983, p. 15). Mishler's (1984) classic research about provider-patient communication described how patients' own experiences, the "voices of the lifeworld" are stifled. When the patient is not restricted by the dominant style of question asking used by the physician (Mishler, 1984), or the manner in which information is presented (Miyaji, 1993; K. M. Taylor, 1988) perhaps more of the patient's perspective will be heard and utilized in decision making. The value that a patient places on treatment outcome is closely associated with the outcome's effect on perceived quality of life. Therefore patients are the best sources of data to measure the quality of treatment outcomes (Kassirer, 1983). Insufficient weight accorded to patients' values and preferences is a hazard that may occur when care givers assume control over decision making. Implied consent may be assumed by providers when patients feel too intimidated to ask questions or voice their preferences.

Patients' have cognitive authority of their experiences, goals and values. The initial step in patient-provider sharing of decision making control is mutual respect for the others' realm of cognitive authority

(Monaco, 1992). Sharing control is a transactional process that occurs between individuals in a relationship (Northouse & Northouse, 1987). When decisions are made for patients on the basis of the health care provider's experiences, goals, and values without consideration of the patient's experiences, goals, and values, the health care provider demonstrates a lack of respect the patient's realm of cognitive authority. Speculating on the reasons for this disrespect, this author suggests that these health care providers may believe they know patient's experiences, goals, and values better than the patient or they may believe the patient's experiences, goals, and values have no place in the medical decision making process.

Patients who desire to have their experiences, goals, and values taken into consideration during treatment decision making, may manifest a preference to take an active or collaborative role in treatment decision making. Patients who believe that the care giver knows their experiences, goals, and values or who feel that their experiences, goals, and values have little importance in treatment decision making may prefer a passive role.

Models of Client-Provider Relations

Roter's (1987) models of client-provider relations were chosen because they can be related to the concept of cognitive authority in both the patient and the health provider in medical decision making. They can also be related to Brickman et al.'s (1982) medical and compensatory models of helping and coping and to Degner and Russell's (1988) dimensions of patient preferences to keep, share or give away decision making control. Roter (1987) described three models of client-provider relations: authoritative-guidance, non-directive, and partnership. The decision making control and responsibility dimensions of Roter's (1987) models of client-provider relations are illustrated in Figure 1.

Roter (1987) argued that the partnership model is superior both to patients making independent decisions without direction from the health care provider and to health care providers using the authoritative-guidance model.

Authoritative-Guidance Model

The authoritative-guidance model connotes the paternalism inherent in the traditional medical model. In this model a dominant authoritarian provider controls medical decision making by claiming a right and a responsibility to make decisions in the best interests of the patient (Roter, 1987). Patients who prefer to "give away" treatment decision making control to their health care providers would be comfortable in this model. The patient and provider's roles in Brickman's (1982) medical model and Roter's (1987) authoritative-guidance model are equivalent.

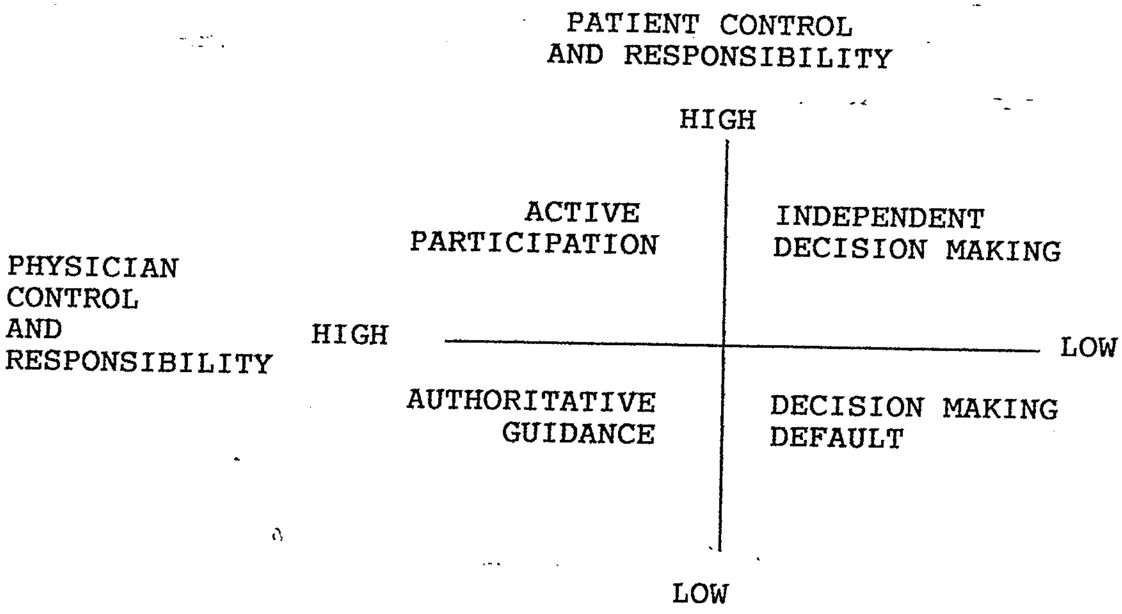


Figure 1. Decision making control and responsibility dimensions of client-provider relations. From "An Exploration of Health Education's Responsibility for a Partnership Model of Client-Provider Relations" by D. Roter, 1987, Patient Education and Counseling, 9, p. 27.

Non-Directive Decision Making Model

Patients in Roter's (1987) non-directive model assume complete responsibility for and control over medical decision making. Providers in this model act as technical consultants. Patients who would be comfortable in this model would be those who prefer to keep decision making control. These patients might be similar to patients in Brickman et al.'s (1982) compensatory model who prefer an active role in decision making. Few cancer patients prefer this type of role in treatment decision making (Degner & Russell, 1988; Degner & Sloan, 1992; Sutherland et al., 1989). If a provider exercised low control and assumed low responsibility for treatment decision making with a patient who preferred a passive or collaborative role, the patient might feel stressed by being compelled into taking unwanted responsibility for treatment decision making. Without the support and guidance of their health care providers, even well informed patients may become overwhelmed (Roter, 1987). Roter (1987) has suggested that patients require meaningful assistance in the form of the provider acquiring an understanding of the patient's perspective and the patients acquiring an appreciation of the real options and their consequences.

Partnership Model

According to Roter (1987), high levels of control and responsibility are needed by both the health care provider and the client to assume the partnership model in health care decision making. Roter's (1987) active participation model expanded Szasz and Hollender's (1956) mutual participation model to include pertinent psychosocial information in the melding of client and provider perspectives. Through disclosure and discussion the provider takes the time to learn the client's perspective of the situation and the client learns about the available options and their consequences.

After both provider and patient share pertinent aspects of their bodies of knowledge with each other they are ready to make decisions together. Both parties have high levels of control, and both parties command respect for their own spheres of cognitive authority. The client respects the provider's medical knowledge; the health care provider respects the client's knowledge of his or her experiences, goals and values.

However, as indicated earlier in this chapter, cancer patients have demonstrated deficiencies in recall, comprehension and application of information given to them. Educators have found that learning is facilitated when the learner is motivated to learn the subject matter. Care givers should determine patients' reasons for wanting information (Husted & Husted, 1991). Is the information needed because participation in decision making is wanted, or is it wanted for some other purpose? Patients who want to be involved in the treatment decision making process want not just to be informed, but to understand the information so that it can be used to come to an informed decision. These patients may identify a need for specific information that patients who prefer to give away decision making control would prefer to not hear. Explanation of specific technical information may require more time than is currently allotted. Evaluation of patient learning after teaching has taken place may also require more time than is reasonably available. Therefore reinforcement and evaluation of learning may need to be delegated to nurses. Determining the topics of information that patients see as relevant is also important. For patients who want to participate in postoperative care decisions, it is important to find out which decisions they feel are most important to participate in because these are topics about which they will need information.

Providing emotional support along with appropriate educational interventions, on the topics in which participation is most wanted, may help empower patients to obtain needed information and to assume their preferred level of control over the decisions that effect their care (Leinster, 1994). Involving patients in treatment decision making may improve outcomes.

Patients in the mutual participation model prefer to share decision making responsibilities with the health care professional. Their health care professionals should respect the cognitive authority patients have about their experiences, goals, and values. Patients in the mutual participation model can be equated to patients in the compensatory model who prefer a collaborative role with the provider to resolve their health problems. The patients in both these models can use the health care provider's expertise as a resource. The difference between the mutual participation model and the compensatory model is that health care providers in the mutual participation model continue to maintain high responsibility for the decisions by providing support and guidance. To maintain standards of care, the provider needs to retain responsibility for treatment decisions.

Summary

Brickman et al.'s (1982) models of helping and coping provided an explanation of why some patients prefer to take active or collaborative roles in treatment decision making and others prefer to take a passive role. Wilson's (1983) conceptualization of cognitive authority provided a partial explanation why some patients do not assume a decision making role when this is what they desire. Roter (1987) suggested that shared decision making control and responsibility, where the experiences, values, and goals of the patient and the health care provider are both taken into consideration, is superior to models of client-provider relations were decision making is borne solely either the client or the provider when treatment decisions are made.

Shared control of treatment decision making has been represented as the theoretical ideal. Beliefs about who should be responsible for treatment decisions is a factor that effects the extent to which patients and practitioners are ready to share decision making and the extent to which they mutually share and understand information. Cronenwett (1983) has suggested that congruence between patient and practitioner models of helping and coping is the key to effective helping. Empowerment of patients in meeting the tasks imposed by the diagnosis and treatment of cancer requires caregivers to provide opportunities for and give permission to patients to assert their competence in a relationship that acknowledges mutual respect for the other's sphere of knowledge (Monaco, 1992). This study examines only the patients' perspectives of the decision making relationship.

CHAPTER 2

LITERATURE REVIEW

The review of the literature provides a background for understanding preferences of patients' roles in treatment decision making, patients' perceptions of decision making role achievement in the patient-practitioner relationship, and the relationship of information to decision making roles. The focus of this study is on the patient's view of the patient-provider decision making relationship and the effect that information has on this relationship.

Figure 2 depicts the manner in which the literature review is organized. The literature was organized in this manner to show a logical progression from preference for an action to carrying out that action: from preference for participation to actual participation to treatment decision making. Because the literature on information is vast, the information seeking and needs literature will be restricted only to pre-discharge, postoperative, recently diagnosed cancer patients or to decision making. Since culture has an effect on information and decision making practices (Holland, Geary, Marchini, & Toss, 1987; Newall, Gadd, & Priestman, 1987; Sarell & Baider, 1984), the literature review will be restricted to western oriented cultures. Methods used to compile the literature review included a manual search, computer search and tracking of citations.

1. Role Preferences in Health Care Decision Making
    - Methods, Instruments, and Populations
    - Situational factors
        - Type and Severity of the Illness
        - Experience in the Patient Role
        - Physician Behaviours
    - Intrapersonal Factors
        - Information Preferences
        - Medical Knowledge
        - Satisfaction
        - Psychological Status
    - Demographic Factors

2. Actual Participation in Health Care Decision Making
    - Outcomes of Patient Participation in Decision Making
        - Questionable Outcomes
        - Positive Outcomes
        - Neutral Outcomes
    - Decision Making Roles
        - Observed
        - Hypothetical
        - In Practice
        - Recommended
    - Patient and Professionals' Role Perceptions
    - Barriers and Enhancers of Patient Participation
        - Patient Preferences
        - Information Seeking
        - Partnership Building
            - Caring
            - Information Giving
            - Beliefs
        - Health Care Delivery System Knowledge
            - Information Needs
            - Discharge Teaching
            - Comprehension

Figure 2. Organization of the literature review.

Role Preferences in Health Care Decision Making

Till, Sutherland and Meslin (1992) listed three criteria for differentiating a preference from a petty want or desire. (a) A preference represents a sincere attempt to weigh and ponder various options and assign values to their outcomes. (b) A preference requires deliberation about something of meaning and importance rather than a gratification of a temporary desire. (c) A preference that is not congruent with past deliberations is suspect. The preference under consideration in this section pertains to the person or persons who make treatment decisions.

Methods, Instruments, and Populations

Research conducted to investigate preference for participation in decision making has had varying results depending on the methods and instruments used and the population investigated. Studies (Beisecker, 1988; Beisecker, Helmig, Graham & Moore 1994; Ende, Kazis, Ash & Moskowitz, 1989; Ende, Kazis & Moskowitz, 1990; Thompson, Pitts & Schwankovsky, 1993) that used scales to determine a numeric value of preference for participation in decision making will be considered first.

Beisecker (1988) asked 106 medical rehabilitation outpatients about who they thought should take responsibility: the doctor, the patient or both in making 13 different medical rehabilitation care decisions. Some of the decisions to be considered by the respondents required medical knowledge such as: what information should be covered in the patients' medical history, which drug to use, and whether the patient should undergo diagnostic tests. The numeric value obtained by patients indicated that authority for decision making should reside, in general, with the physician. Only 6.1% of the sample felt that they should have more responsibility that the physician. Older patients wanted significantly less responsibility than younger patients. Although this study is included in preferences for participation, it really did not measure preferences. Rather, it measured beliefs about where authority should reside. Believing something <u>should</u> be done in a certain manner is different than <u>preferring</u> to do it in that manner. For example: Some people know or believe they should avoid eating fried food but they prefer or desire to do so. Beisecker lead the reader to believe that "desire" for input into decision making was measured rather than the precept. Desire or preference to do something and belief that one should do something, although different, are closely related. For some people, precepts are more forceful in guiding behaviour and in other people, preferences are more forceful. The study also examined preferences for information, but this will be described in a later section.

Beisecker et al. (1994) adapted Beisecker's (1988) instrument when measuring 288 women outpatients' attitudes about who should have responsibility in making treatment decisions for breast cancer patients. None of the women were diagnosed with breast cancer. The women were required to imagine they had breast cancer when completing the questionnaire. A cancer diagnosis is seen as a crisis situation by those who have experienced it (Hagopian, 1993). What people imagine they might do and what they actually do during a crisis are often quite different. Therefore the validity of the women's responses may be questioned. The study would have been stronger if breast cancer patients were the subjects. The women's mean score indicated that they felt that more of the responsibility should reside with the physician than with themselves in making treatment decisions. However, when asked how they might change their responses if they were older or younger, women favoured equal participation in treatment decision making. The majority indicated that they would rely on the physician for an expert medical opinion but the patient should have the final authority in making the decision. The responses of the women to the open ended question clashed with their score results. From the researchers' description of the items on the questionnaire, it would appear that medical knowledge would be required to make the decisions. Since the women did not have breast cancer, they might not have sought information that they may have required to feel confident in taking responsibility for the decisions listed on the instrument. Also, the tool might not have sufficiently captured women's actual beliefs about their decisional role preferences. Responses to the questionnaire and the open ended question might have been more congruent had the items on the questionnaire included how the decisions could effect patients' quantity and quality of life. The researchers also surveyed oncologists and oncology nurses. Their responses will be described in a later section.

Ende et al. (1989) developed the Autonomy Preference Index (API) which also required subjects to consider, in detail, situations that require medical knowledge with which they might not have had any personal experience. The API included six general items and nine specific items related to three vignettes, in ascending order of severity, that dealt with day to day medical decisions. Another section of the API assessed information preferences. The information preferences aspects will be described in a later section.

Respondents in Ende et al.'s (1989) study chose the amount of responsibility they preferred on a scale of 1 to 5. A random selection of patients attending a hospital-based primary care clinic (n = 312), were to imagine they were the patients in the vignettes. The subjects wanted physicians to have most of the responsibility when making these decisions. As the severity of illness portrayed in the vignette increased, the subjects wanted less responsibility. The subjects' illnesses that they had themselves were not taken into consideration. Their actual experiences with the illnesses portrayed in the vignettes may have had an effect on the results. Perhaps the subjects felt they did not have sufficient knowledge or personal experience to make these types of decisions. The researchers concluded that patients did not want a role in decision making. These patients were not saying that they did not want a role in decision making, they were saying that they wanted less of a role in treatment decision making than their physicians when they made their selections on the scale from 1 to 5.

Ende et al. (1990) had 151 physicians complete the API and then compared physician responses to patient responses from the Ende et al. (1989) study. The physicians were asked to respond in terms of their own preferences when they are patients. Rather than having respondents select a numerical value from 1 to 5, respondents were to select who should be making the decisions: physician alone, patient and physician equally, or patient alone. The instrument did not provide the respondent an opportunity to select partial but not equal patient responsibility for decision making. Physicians wanted more responsibility than non-physicians. However, physician responses were similar to non-physician responses in that both groups wanted their care providers to assume most of the decision making responsibility and, as the severity of the illness increased, both groups wanted their care providers to have increasing responsibility. Physicians who were themselves seeing a physician on a regular basis responded differently from the other physicians only in the most severe illness vignette: Physicians who were also patients wanted the same amount of responsibility as non-physicians.

Because physicians in the Ende et al. (1990) study wanted more control in decision making than non-physicians in all the vignettes, it would appear that the amount of medical knowledge patients have influences the amount of decision making responsibility to which they think they are entitled. Since only in the most severe illness vignette, responses of physicians who were personally seeing a physician on a regular basis were significantly different from other physicians but not significantly different from non-physicians, this indicates that, in cases of severe illness, current experience in the patient role decreases preference for taking responsibility in treatment decision making. Current experience in the patient role seems to be a more powerful factor than medical knowledge in cases of severe illness. When people are currently experiencing the patient role, the threat of severe illness, may make them feel less confident in taking responsibility for decision making even though they are knowledgeable.

Thompson et al. (1993) adapted the vignette part of the 1990 API to include partial responsibilities and developed another instrument, the Desire for Involvement Questionnaire (DIQ) that tested health maintenance organization members (n = 459) preferences for decision making in medical situations that did not require medical knowledge. The DIQ was structured so that the results could be easily compared to the API. Each of four vignettes described a different medical problem for which there were two equally appropriate medical treatments, but the treatments had differing lifestyle implications for the patient. The respondents were to imagine themselves in the situations and were asked to select who should decide which of the two treatments they should receive in each vignette. The patients believed that they should have an equal or greater share of responsibility when making decisions about medically equivalent options that affected their lifestyle (DIQ) but when making decisions that required medical knowledge (API) they would rather the responsibility be borne by their physicians.

The DIQ tapped the knowledge that patients bring to the patient-health care provider interaction. They felt confident in their knowledge of themselves and wanted to use it in making treatment decisions. Patients' preferences for decision making control in the Thompson et al. (1993) study varied depending on the situation depicted in the vignette on DIQ, but on the API, patients' preferences were similar to Ende et al. (1989)'s patients' preferences. Thompson et al. asked respondents if they had any of the illnesses portrayed in the vignettes. They found that only patients who had hypertension (n = 65) wanted less control in the hypertension vignette. Hypertension was more than twice as common as the next most frequent illness among the subjects. Thompson et al. speculated about why people with hypertension want less control. Thompson et al. demonstrated that when people are asked to use the knowledge they have of themselves, they want to participate in treatment decision making. However, they are hesitant to participate if medical knowledge is required. They feel less confident about using medical knowledge than using knowledge about themselves.

Hillmann (1994) developed a decision making questionnaire which was tested on 81 patients who were admitted to and discharged from either a medical intensive care unit or a cardiac care unit and on proxies of the patients' choice. There were no significant differences between patients and proxies: Both preferred to share in decision making with the physician. This study informs health care providers that patient-appointed proxies prefer to take the same decision making roles as the patients they represent. It also indicates that some patients who are critically ill, prefer to share decision making control when measurement is on a scale. However, the scale had a weak test-retest reliability because of small sample size and lack of variability in responses.

Krantz, Baum, and Wideman (1980) developed the Health Opinion Survey (HOS) which measures a general predisposition for seeking information and becoming involved in one's health care. Involvement could mean interacting with the health care provider or carrying out a plan of prescribed action or making treatment decisions. The scale is not specific to treatment decision making. It is referred to in this section because this scale has been used in experimental studies to determine the effects of preferences for behaviourial involvement in health care on actual patient decisions. These studies will be described in a later section.

Scales are somewhat taxing to carry out when a person is ill person or when a subject is required to complete many questionnaires. Therefore a less demanding type of instrument is often used in these instances. Instruments that are not scales will be discussed next.

Blanchard et al. (1988), Brandt (1991), and Cassileth, Zupkis, et al., (1980) obtained similar results when they used an instrument that requested cancer patients to select either: "I prefer to leave decisions about my medical care and treatment up to my doctor;" or "I prefer to participate in decisions about my medical care and treatment." Cassileth, Zupkis, et al. surveyed 256 patients, 56% of whom were outpatients, Blanchard et al. examined 439 interactions with hospitalized patients, and Brandt studied 22 patients who were hospitalized and undergoing radiation implant therapy. The majority (Blanchard et al., 69%; Brandt, 59%; Cassileth, Zupkis et al.,67%) preferred to participate. The instrument allows only discrimination between those wanting absolutely no input into decision making from the rest of the sample. It does not allow determination of the degree of preferred participation. Participating could have meant that they wanted very little to a great deal of responsibility in treatment decision making. These studies also included information components that will be discussed in a later section.

Instruments that allowed respondents to choose a decision making role from a range of roles with differing levels of responsibility will be discussed next. Brody, Miller, Lerman, Smith and Caputo (1989) asked 117 clinic patients, the majority of whom had relatively minor illnesses, to select their preference for one of the following decision making roles: (a) "The doctor takes the initiative and decides what is best for me." (b) "The doctor considers some of my ideas but still makes most, if not all of the final decisions." (c) "The doctor and I make the final decisions together." (d) "I make all the final decisions." Only those who chose roles (c) and (d) were considered to prefer an active decision making while the other two roles were designated as passive. An active role was preferred by 68% of the patients. Brody et al.'s instrument measured respondents' decision making relationship with their physicians in a global manner. Outcomes that were associated with patients' role perceptions were measured and will be discussed in a later section.

Strull et al. (1984) measured the decision making relationship of hypertensive patients (n=210) and their practitioners (n=50) with regard to a specific treatment. They were asked how they thought decisions about their medications should be made. The researchers divided the data collection instrument into five incremental categories of decision making responsibilities. The researchers in this study asked respondents who "should" make decisions and interpreted their responses as preferences. Nearly half the patients (47%) selected the most passive role offered, 33% chose the next passive role. Only 19% of the patients picked decision making on an equal basis with the practitioner and 3% made selections from the two categories attributing more responsibility to the patient than the practitioner. The practitioners overestimated the amount of decision making control that the patients preferred. Hypertensive patients' decreased preference for participation in decision making was substantiated by Thompson et al. (1993), who found that respondents who had hypertension wanted less decision making responsibility when it came to making decisions about the treatment of hypertension. Is there something about having hypertension that predisposes a person to want less decision making control? The long term need for these patients to be under medical supervision may be a contributing factor.

All of the previous described studies were American. In Canada, Sutherland et al. (1989) adapted the patient questionnaire developed by Strull et al. (1984) to use with a convenience sample of 52 ambulatory cancer outpatients undergoing radiation or chemotherapy and found that 63% believed it was ideal for the doctor alone or mainly the doctor to make decisions, 27% felt decisions should be shared and 10% felt the patient should have a major role. Using the same tool, Llewellyn-Thomas, McGreal and Thiel (1995) found that colorectal patients' (n=90) decision role preferences were fairly evenly distributed: 37% preferred a passive role, 31% preferred a collaborative role, and 31% preferred an active role when they were asked about a hypothetical chemotherapy treatment.

All of the preceding studies have required respondents to answer a questionnaire. Degner and Russell (1988), also Canadians, used the Control Preference Card Sort (see Appendix M) to elicit data from their respondents. The instrument consisted of four cards that encompassed a range of role preferences, each describing a level of decision making control in a relationship with the physician. When the cards were presented in pairs to a subject the investigator asked, "Which of these do you like the best? Which one would you prefer to have in your care?" The card sort method allowed for prioritization of preferences rather than picking only one. As well, it allowed for an opportunity to closely compare and weigh each of the roles. Degner and Russell (1988) tested their decision making role card sort on a theoretical sample of 60 ambulatory cancer patients and concluded that there was an underlying psychological dimension of keeping, sharing and ceding control. To ensure that patients who typified all dimensions of keeping, sharing and ceding control would be included in the sample, the subjects were selected accordingly. Patients who preferred to keep control were difficult to accrue because several of them discharged themselves from treatment. Most patients in the sample preferred to share control over treatment decision making when selecting subjects.

Degner and Russell's (1988) instrument was modified to include five levels of decision making control, the wording was condensed and a cartoon illustration depicting the wording was added. Using the new and improved cards, Degner and Sloan (1992) surveyed 436 newly diagnosed cancer patients and 482 members of the general public in Winnipeg who did not have cancer. Subjects compared each card with every other card to determine their preference orders across the set of five cards. Subjects whose first choice was "I prefer to make the final selection about which treatment I will receive," or "I prefer to make the final selection of my treatment after seriously considering my doctor's opinion," were labelled as preferring an active role. Subjects whose first choice was "I prefer that my doctor and I share responsibility for deciding which is best for me," were labelled as preferring a collaborative role. Those whose first choice was "I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion," or "I prefer to leave all decisions regarding my treatment to my doctor," were labelled as preferring a passive role.

The preference orders of the majority of the patients and members of the general public suggested that both groups had different systematic preferences along the psychological dimension of keeping, sharing or ceding decision making control. Most cancer patients wanted a passive role in decision making while most members of the general public, if they developed cancer, wanted an active role. The proportion of patients preferring passive, collaborative and active roles was consistent with Sutherland et al.'s (1989) findings. The wide differences in preferences for decision making control between cancer patients and members of the public, when they were requested to answer as if they had cancer, casts doubt on the validity of studies (Beisecker et al., 1994; Ende et al. 1989, 1990; Thompson et al., 1993) that assessed preference roles by asking subjects to imagine themselves in another's place because a person's current situation can temporarily change long term preferences (Christensen-Szalanski, 1984).

Other Manitoba researchers (Bilodeau, 1992; Davidson, 1993; Hack, 1991; Hack, Degner & Dyck, 1994; Kaprowy, 1992) have used the five card instrument developed by Degner and Sloan (1992). Hack (1991) and Hack et al. (1994) used the card sort to determine the decision role priorities of 35 stage I and II ambulatory breast cancer patients: 57% preferred a collaborative role, 23% preferred an active role and 20% preferred a passive role. The researchers also determined the relationship of decision making preferences to information preferences. This relationship will be described in a later section. Bilodeau found that most breast cancer patients wanted a collaborative role. Davidson found that men with prostate cancer prefer a passive role. Kaprowy found that most end stage renal disease patients preferred a collaborative role in treatment decision making.

The large proportion of cancer patients preferring to participate in decision making that Bilodeau (1992), Blanchard et al. (1988), Cassileth, Zupkis et al. (1980), and Hack et al. (1994) found was inconsistent with Degner and Sloan's (1992) and Sutherland et al.'s (1989) findings. One of the explanations for the differences put forward by Degner and Sloan (1992) was that the Cassileth, Zupkis et al. instrument might have placed patients whose preferred level of participation in decision making was relatively passive (ie. providing information that the doctor should consider) together with patients who preferred active or collaborative decision making roles. It also appears that breast cancer patients prefer more involvement in treatment decision making than other cancer patients.

In England, three qualitative studies were carried out. Waterworth and Luker (1990) conducted interviews with a convenience sample of 12 patients on three medical wards about the way they elicited information, their perception of the process whereby nursing care decisions were made, patient rights, and the individuals's responsibility for health care. One major theme, "toeing the line," was identified. These patients were concerned with staying out of trouble and were willing to relinquish their freedom and responsibilities in order to accomplish this. The fact that patients experienced uncertainty but were reluctant to ask questions in a straightforward manner was interpreted as a possible demonstration of patients' acceptance of their lack of involvement in decision making and their perception of not having the right to do so. Patients feared that punitive action might be taken against them if they did not cooperate with the medical and nursing care that had been planned for them. These patients voiced their trust in health care providers and acknowledged a competence gap between patients and providers. The researchers concluded that patients who do not want to take a collaborative role in planning their care might be coerced into doing so because of their overwhelming desire to "toe the line." No description of the patients was reported.

The patients in Waterworth and Luker's (1990) study demonstrated a qualified trust in their care providers. The patients appeared to be trusting that their care providers would care for them appropriately but only if the patients behaved the way they thought their care providers wanted them to behave. They seemed to fear what would happen to them if they did not behave. In the hospital environment, participation in decision making was not a precept. These patients followed the rules. They did not consider preferences.

Biley (1992), used a modified grounded theory approach to analyze the determinants of patient participation in decision making about nursing care. Eight postoperative patients who had been home from hospital for 7 - 10 days were interviewed. Three second order categories emerged: "If I am well enough...", "If I know enough...", and "If I can...". Patients who assessed themselves as more ill wanted less participation. As they recovered from surgery and they perceived that their health had improved, they wanted more participation. Patients who assessed themselves as having less knowledge about a particular situation wanted less participation in that situation. In situations where they perceived themselves to have more knowledge, they wanted more participation. Health care organizational constraints limited the choices available to patients about issues such as sleep, rest, hygiene and nutrition.

Avis (1994) explored patients' perspectives in a day surgical unit using non-participant observation of 12 patients in a pre-surgical assessment clinic and 10 postoperative patient interviews. The patients saw themselves as the professional's "work object" much like a car that is being taken in for servicing. Avis concluded that patients' view of themselves seemed to restrict their concept of themselves as collaborators in their care.

As can be seen, inconsistent results were the product of varying methods, instruments and populations. Attention will now be turned to situational, intrapersonal and demographic factors that influence preferences for participation in decision making.

Situational Factors

Severity of illness, experience with the situation, and physician behaviours are situational factors that affect a person's preference to participate in decision making.

Type and Severity of the Illness

Type of illness may effect decision role preferences. Patients who had relatively minor illnesses 78% preferred an active role in decision making (Brody et al., 1989). The majority of hypertensive patients preferred that physicians have more responsibility than patients in making decisions (Charles et al., 1984). The majority of Canadians with varying types of cancer preferred a passive role in decision making, but those with breast cancer preferred a collaborative role (Bilodeau, 1992, Degner & Sloan, 1992, Hack et al., 1994, Sutherland et al., 1989).

Preference for participation in treatment decision making is effected by severity of illness. The Ende et al.(1989, 1990) demonstrated that as severity of illness increases, people have a tendency to prefer less input into treatment decision making. Ende et al.'s (1990) physician subjects who were themselves seeing a physician, wanted less treatment decision making control than the other physicians when considering a severe illness. As Biley's (1992) patients resumed their health they wanted more participation.

Varying effects of cancer on decisional role preference have been noted. Dennis (1987) found that cancer patients represented the majority of those who wanted to be involved in diagnostic and treatment decision making. However, Degner and Sloan (1992) demonstrated that patients diagnosed with cancer preferred to give away decision making control while people who do not have cancer preferred to keep it. Blanchard et al. (1988) found that cancer patients who had a lower functional status wanted less decision making control and that those who had a prognosis of less than three months or greater than one year were more likely to prefer participation in decision making. A cancer diagnosis is frequently associated feelings of increased distress, anxiety, fear, depression and helplessness (Krause, 1993). Generally, it would seem that people tend to prefer to give away control over decision making when they are acutely ill and want progressively less control as their illness worsens. However there seem to be several exceptions to this general observation. If patients become terminally ill, they prefer to keep decisional control (Blanchard et al., 1988), perhaps because they realise that the care provider has no cure. Cassileth, Zupkis et al. (1980) found that ambulatory or non-ambulatory status and inpatient or outpatient status had no effect on decision making preferences.

The studies in which cancer patients were subjects had varying results. The different ways in which preference for participation was measured is probably the biggest source of inconsistency. Therefore it is difficult to draw firm conclusions. Also, one cannot discount the effect that culture might have had in these studies as well. Those studies the were carried out in the United States often, but not always, showed a greater preference for participation than those completed in Canada and the United Kingdom.

Experience in the Patient Role

Thompson et al. (1993) found that only previous experience with hypertension had a negative effect on preferences for participation in decision making. They suggested that perhaps patients with chronic illnesses do not feel self-confident or qualified in assuming a collaborative role in decision making when they realize the difficulties involved in treating their illnesses. Physicians who were currently seeing a physician themselves wanted less input into decision making than other physicians when making decisions about a serious illness (Ende et al 1990). Perhaps current experience in the patient role highlights one's personal vulnerability. If there are unwritten rules that are to be followed during practitioner-patient encounters, vulnerable feeling patients will not risk their health in order to participate in decision making (King, Norsen, Robertson & Hicks, 1987).

Patients in the Waterworth and Luker (1990) study were fearful of breaking the unwritten rules. Fisher (1988) found that patients who did not conform to the usual patient role and questioned physicians' authority lead the physician to change the topic to morality. Shye, Javetz and Shuval (1990) found that Israeli health care professionals do not have a positive view of patients' expressions of autonomy related to patients' lay referral network, bargaining with the physician during the medical encounter, patients' modification of prescribed treatment, and information seeking behaviours. The researcher found that patient behaviours that threatened the physician's dominance over treatment decisions were rejected outright. Female residents and general practitioners held the most negative views while allied health professionals had less negative views. Treatment decision making was viewed as the physician's exclusive domain. Perhaps patients who have encountered health care professionals who believe that patients should not be participating in treatment decision making, have dampered patients' feelings of self-confidence about having input into treatment decision making.

Degner and Sloan (1992) found that actual experience as a cancer patient had a massive effect: People who did not have cancer had opposite preferences for participation in decision making to people with cancer. Even practitioners are inaccurate in their assessments of patients, preferences for participation and information (Strull et al., 1984). It can be concluded that if a researcher wants to know what a population believes, the people from that population should be sampled. When people are asked to imagine themselves in roles, their imaginations may be quite different than the real situation. Experience in the role of a patient has an effect on one's preferred role in treatment decision making.

Physician Behaviours

Blanchard et al. (1988) found that patients cared for by physicians who addressed clients by their first names, attempted to establish privacy during physical examinations, examined patients on their chests and abdomens, and discussed test results with patients, were more likely to prefer participation in decision making. These behaviours connote caring and information giving. Although there are other studies that describe physician behaviours, this is the only one that related them to preferences for participation in decision making. Studies that relate physician behaviours to actual participation will be reviewed in a later section .

Situational factors such as type and severity of illness, the experience of being a patient, and physician behaviours affect preferences for participation in decision making.

Intrapersonal Factors

Information Preferences

In studies that measure the association of information preferences to decision making preferences, most cancer patients want maximal information. Lack of information has been associated with increased uncertainty, anxiety, distress and dissatisfaction (Fallowfield, 1993). However, information preferences are sometimes associated with decision making preferences and sometimes they are not. Information needs will be discussed in a later section.

Information preferences associated with decision making preferences. Brandt (1991), Blanchard et al. (1988), and Cassileth, Zupkis, et al. (1980) used the same instrument and found that most cancer patients desired maximal information (86.4%, 92% and 71.3% respectively) about their illness. The majority of patients in these studies also wanted to participate in treatment decision making (59.1%, 69%, 66.7% respectively). In Cassileth, Zupkis, et al.'s study, information and decision making role preferences correlated so strongly (P<0.0001) that the researchers suggested that information and decision role preferences represented a single attitude. Blanchard et al. and Brandt did not find significant correlations.

Using Q methodology, Dennis (1987) found that some patients who wanted information about diagnostic tests and treatment did not reveal a desire for participating in treatment decisions while other patients did want to be involved making treatment decisions. Tattersall, Butow, Griffin, and Dunn (1994) found that 80% of 182 cancer patients visiting an oncologist for the first time wanted all information and 72% wanted to participate in treatment decision making. Sutherland et al. (1989) and Hack et al. (1994) noted that patients who preferred active participation in treatment decision making sought more information that those who preferred a passive role. Hillmann (1994) found that patients who had been admitted to and discharged from either a medical intensive care unit or a cardiac unit wanted maximal information, and they wanted to share in decision making.

Cassileth, Zupkis et al. (1980) found that cancer patients who were younger, better educated and more recently diagnosed wanted more detailed information. The researchers found that ambulatory or non-ambulatory status and inpatient or outpatient status had no effect on information preferences. Beisecker (1988) found that older patients did not even believe that they had a right to the information.

Hack et al. (1994) found that stage I and II breast cancer patients who preferred to take an active role in decision making, statistically differed from passive patients in the following manner: (a) Active patients preferred more technical detail during the disclosure of their diagnosis. The predictability of passive patients preferences about the amount of detailed information, when their diagnosis was disclosed to them, could not be determined. (b) Active patients preferred a written copy of the diagnosis rather than a taped one but passive patients preferred either a written copy or no copy at all. (c) All active patients preferred the physician to use the terms cancer or malignancy rather than a euphemism, while 75% of the passive patients preferred a euphemism. (d) Active and collaborative patients preferred complete information about all major treatment alternatives but passive patients wanted to hear only the single best treatment or nothing at all. (e) All active patients and the majority of collaborative patients preferred to hear detailed information about their treatment procedures. Passive patients were evenly divided between wanting detailed information or brief/no information. The researchers found that majority of all patients, active and passive, wanted detailed information about side effects. Differences between active and passive patients' preference for information about prognosis was not statistically significant.

Information preferences not associated with decision making preferences. Blanchard et al. (1988) found that only 75% of hospitalized cancer patients preferring to hear all news, both good and bad, also preferred to participate in decision making. Brandt (1991) found that although 86% of 22 cancer patients receiving radiation implants desired maximum information, only 59% preferred to participate in decisions about their care. Sutherland et al. (1989) and Hack et al. (1994) found that some passive patients (63% and 25.7% respectively) preferred to have detailed information.

In the Beisecker (1988) and Ende et al (1989) studies, patients' desire for information was strong but it was not significantly related to their decision making preferences. Beisecker's information scale was particularly relevant to the decisions considered in the study because the items for both decision making and information preferences were the same. The patients in Beisecker's study rated, on a scale from 1 to 5, how important it was for them to have information about each decision. All respondents, young and old, desired an overwhelming amount of information. Although patients wanted an abundant amount of information, most believed that they had less responsibility for making medical decisions than their physicians.

Ellis and Leventhal (1993) studied the information preferences of 50 paediatric cancer patients (ages 8 - 17) and their parents. The researchers found that the children wanted information on all aspects of their disease and its treatment, particularly prognosis. Most of the children (76%) wanted to know a percent chance of cure, no matter what it was. Only 38% of parents wanted their children to receive this information. Most children (95%) wanted to be told if they were terminally ill. Those children who were more knowledgeable of their illness (could state the diagnosis and read consent forms) perceived a more active role in decision making than those with a limited understanding. The majority of children and parents perceived that treatment decisions were made by the physician. Most children (96%) did not want to make their own decisions about curative therapy, but 63% of adolescents and 28% of younger children wanted to participate in palliative treatment decisions.

To conclude this section, it can be said that if the preference level for participation in decision making is low, then information preferences are often not associated. However, when subjects prefer to participate in decision making, there is usually an association. Since preferences were measured on varying scales and there were some inconsistencies in the results of studies a firm conclusion cannot be reached. Hack et al. (1994) suggested that lack of specificity about the type of information wanted may have contributed to the problem. It can only be said that people who prefer to participate in treatment decision making also prefer to receive information about the illness and it's treatment. Those who do not wish to participate sometimes want and sometimes do not want to receive the information.

Medical Knowledge

Inferences about the effect of medical knowledge on patients' preference to participate in decision making can be drawn from several studies. Patients who preferred not to engage in treatment decision making felt that they were not qualified to take part (Cassileth, Zupkis et al., 1980). Blanchard et al. (1988) found that patients of physicians who had discussed test results with patients preferred to participate in decision making. It may be implied that patients receiving such a discussion would be more knowledgeable about their medical condition that patients who did not receive such a discussion. Biley (1991) found that patients who assessed themselves as having less knowledge about a particular situation wanted less participation in that situation. But, in situations where they perceived themselves to have more knowledge, they wanted more participation. Physicians wanted more input into decision making than non-physicians (Ende et al 1990). It is generally assumed that physicians have more medical knowledge than non-physicians. Patients preferred to participate in medical care decision making when medical expertise was not required but they had a low preference for involvement in treatment decisions when it was required (Thompson et al, 1993). Therefore, the amount of medical knowledge one has seems to effect desire for input into medical decisions.

Satisfaction

Patients who preferred to participate were less satisfied (Blanchard et al., 1988). Those who were less interested in participating were more satisfied with how decisions were made, and more satisfied with their overall medical care (Ende, 1989).

Psychological Status

Those who preferred to participate in decision making were more hopeful than those that did not prefer to participate (Cassileth, Zupkis, et al., 1980). When asked about participating in decisions that required knowledge of themselves, patients appeared to have self-confidence by preferring to participate in decision making (Thompson et al., 1993). Waterworth and Luker's (1990) patients felt vulnerable and threatened and were more concerned with pleasing their nurses than in participating in decisions concerning their care. In conclusion, it would appear that patients who feel hopeful and self-confident want to participate while those who feel vulnerable and threatened, accept the care delivery system and trust that their care givers will make the right treatment choices on their behalf.

Demographic Factors

In Beisecker's (1988) study, patients over 60 years of age were firm about authority residing with the doctor while younger patients were more in favour of joint control in decision making. However Beisecker et al. (1994) found that a woman's age was not related to her preference for participation in decision making. This may have been because Beisecker et al.'s entire sample was relatively young. Blanchard et al. (1988), Cassileth, Zupkis, et al. (1980), Ende et al. (1989), Llewellyn-Thomas et al. (1995), Strull et al. (1984), and Thompson et al. (1993) found that younger and more educated patients had a greater likelihood for preferring participation in treatment decision making. Thompson et al. found that age and education accounted for 25% of the variance. Beisecker suggested that older people prefer less input into medical decision making because they came of age when physicians were traditional power figures to be revered and obeyed. Less well educated patients believed they did not have the knowledge that is essential in making informed treatment decisions, while better educated patients usually had more illness-related information and or ability to determine the kind and amount of information they needed (Hack et al. 1994).

Females wanted to participate more then males (Llewellyn-Thomas et al., 1995). Males and single people tended to prefer not to participate (Blanchard et al., 1988; Ende et al., 1989). It would appear that preferences for participation in decision making are associated with age, education and gender.

Summary

Decisional role preferences varied when different instruments are used and when different populations are studied. Patients' preference for participation in treatment decision making varied depending on situational, intrapersonal, and demographic factors. Preference for detailed information was usually greater in patients who preferred active decision making roles. Degner and Sloan (1992) demonstrated that the validity of the results of studies (Beisecker, 1994; Ende et al, 1989; Thompson et al, 1993), in which the subjects were to respond as if they had an illness that they did not have, can be questioned. Thompson et al.'s (1993) study underlined the importance of tapping into the type of knowledge patients bring to the decision making situation.

Two of Till et al.'s (1992) three criteria for differentiating preferences from petty wants have been upheld. (1) Preference for participation in treatment decision making represented sincere attempts to weigh and ponder various role options and assign values to their outcomes. (2) Selecting a preference for decision making roles required deliberation about something of meaning and importance rather than a gratification of a temporary desire. However, the third criterion was not supported, role preferences may not remain stable. Longitudinal studies on decision role preferences have not been reported. Since role preferences can be affected by patients' situational and intrapersonal factors, they may change over time.

Actual Participation in Health Care Decision Making

In this section, the following topics will be examined: outcomes of patient participation in treatment decisions, actual decision making roles, patient's and professionals' role perceptions, and barriers and enhancers of patient participation.

Outcomes of Patient Participation in Decision Making

Questionable Outcomes

In an experimental study, King et al. (1987) found that using the Krantz Health Opinion Scale (HOS) was not helpful in determining which patients benefit from having control in managing their pain medications after cardiac surgery. Several patients dropped out of the study so that they could obtain a stronger analgesic. These patients exercised their choice. King et al. speculated that "the variable of interest is not an individual's general disposition as to choice in health care but the actual choice one makes in determining the extent to which one participates in a specific health care activity" (p. 149).

Wallston et al. (1991) used the HOS to determine the interaction effect of desire for control and having control or not having control over the type of antiemetic therapy used by 74 chemotherapy patients with various types of cancer. Patients were randomly assigned to choice or no choice groups. Each no choice patient was yoked to a choice patient. The no choice patient received the same antiemetic treatment that was chosen by the choice partner. Although the experimental intervention was choice or no choice, only a majority of subjects, not all of them, correctly perceived that they were being given a choice or not. It would have been appropriate to drop the subjects from the study who did not correctly perceive whether or not they had a choice. However, all patients really had a choice because they were free to choose to continue or drop out of the study. Patients in the study (Wallston et al., 1991) with a moderate level of desire for behavioral involvement and who were given a choice of type of antiemetic, showed less anxiety, negative mood, and nausea than those who were not given a choice. Patients with either high or low desire for involvement were not affected by the experimental manipulation.

As in a previous study of this kind (Wallston et al., 1987), only subjects who had a moderate desire for involvement benefitted from being given a choice. However, reactance occurred in those with a high desire for involvement (Wallston et al., 1987). The researchers suggested that reactance occurred because the choice between interventions was non-consequential. It was as if they really had no choice. The findings from these studies must be interpreted with caution because the HOS lacks specificity to treatment decision making, and because there were problems with the design of the studies.

Positive Outcomes

Several studies have associated positive outcomes to patient participation in decision making. Brody et al. (1989) examined outpatients with mostly minor illnesses. The patients had the following perceptions: 39% believed that their physicians had made all the decisions, 14% felt that their physicians had made most of the decisions, 44% thought that they and their physicians had shared decision making, and 3% indicated that they had made all the decisions independently. Patients who perceived that they played an active role reported less concern about their illness, less discomfort and disfunction and a greater sense of personal control before visiting their physicians than patients who perceived themselves as passive. One day after the visit, patients who believed that they had played an active role had less concern about the illness, had a greater sense of personal control, and were more satisfied. One week after the visit, patients who thought they had played an active role perceived greater improvements in both their symptoms and overall medical condition than patients who perceived they played a passive role.

During twenty minute sessions prior to visiting physicians, Greenfield, Kaplan and Ware (1985) assisted 23 patients with peptic ulcers in reading their medical records and coached them in asking questions and in negotiating medical decisions with their physicians. Compared to a control group (n=22) who received information about ulcers and a diagram of the gastrointestinal tract, the experimental group reported, six to eight weeks later, fewer limitations in physical role-related activities, a preference for a more active role in medical decision making, and were more satisfied with their care.

Morris & Ingham (1988) compared psychosocial outcomes of early breast cancer patients who had and who had not been offered a choice between mastectomy or breast conserving surgery. They found that offering a choice led to less preoperative psychological complaints, to improved reported adjustments with respect to resumption of work, better attitude toward the future, less worry about disease recurrence, and improved perception of coping with the cancer experience.

Morris and Royle (1988) compared pre- and postoperative anxiety and depression in 30 breast cancer patients who had and had not been offered a choice of surgical treatment. Clinical levels of depression and anxiety were seen preoperatively and for up two months postoperatively significantly more often in women who were not given a choice. Although their anxiety and depression continued, it decreased over time. At 6 months postoperatively, the trend remained but there was no longer a statistical difference between the two groups. The researchers noted that patients who had been offered a choice had similar preoperative levels of anxiety and depression to women with benign breast disease and to patients undergoing surgery not related to cancer. They concluded that breast cancer patients suffer less if they are allowed to take part in treatment decision making.

Fallowfield, Hall, Maguire, & Baum (1990) examined 269 early stage breast cancer patients under the age of 75. Women who were treated by physicians who offered a choice between mastectomy or breast conserving surgery showed less depression that those who were treated by surgeons who did not offer a choice.

Hopefulness has been associated with a preference for participation in decision making (Cassileth, Zupkis et al. (1980). Sardell and Trierweiler (1993) interviewed 10 physicians and 10 cancer patients to determine the procedure used when a cancer diagnosis is disclosed. From this information the researchers compiled a questionnaire to assess cancer patients' (n=56) views about how physicians could enhance hopefulness when the diagnosis is disclosed. The consensus among patients was that certain procedures enhance hopefulness and others reduced it. Physicians discussing all options for treatment, even those not that are not recommended, and the provision of emotional support were included in the disclosure procedures that increased hopefulness. Disclosure procedures that restricted information flow to the patient decreased hopefulness. The researchers suggested it would be best for physicians to determine patient preferences for the conduct of the treatment relationship.

Neutral Outcomes

Levy, Herberman and Lee (1989) found there were no psychological advantages in terms of functional status and self-reports of mood states and perceived social support in women who were allowed to choose between having mastectomy or lumpectomy/radiotherapy when they were compared to patients who were randomly assigned to their treatment. Deming (1989) found that anxiety was not related to breast cancer patients' (n=87) decisional behaviour. Hillmann (1994) observed no relationship between the personality dimension of repression-sensitization to medical decision making or information seeking in critically ill patients.

To conclude, it appears there were either no differences or positive outcomes from involving patients in the decision making process. Studies using the HOS were inconclusive.

Decision Making Roles

Decision making roles will be considered in objectively observed and hypothetical situations and in descriptions of how patient participation in treatment decision making had been integrated into actual practice. Recommendations sited in the literature will be provided.

Observed

Using in-depth interviews and observations to determine issues surrounding the nature of life and death decision making, Degner and Beaton (1987) concluded that most patients in Manitoba assume little to no control in treatment decision making.

Beisecker (1988) found that age and preferences for participation in decision making had no effect on medical rehabilitation patients' consumerist behaviour. On tape recordings of patient-physician interactions, she found that patients, young and old, demonstrated passive behaviour. Although younger patients had indicated that they held consumerist perceptions, as measured on an attitude scale, and recognized they had a right to have input in medical decisions, most did not demonstrate an overt performance of it during patient-physician interactions. Patients over 60 were less likely to believe they had a right to participate in making medical decisions. Although almost half of the older patients wanted no input into decision making, there was no difference between younger and older patients in their actual behaviour.

Fisher (1988) observed information sharing and decision making among female patients and their physicians in two American teaching hospitals over a six year period. She found that the physicians' institutional authority gave them an interactional edge and placed patients at a disadvantage. The researcher found that many women were not given sufficient information to make reasonable decisions. Most patients and physicians believed that physicians knew what was best for their patients and that physicians should be the ones who make medical decisions. Patients usually accepted the treatment recommended by the physician without questioning. When patients did ask questions, they rarely questioned the information presented or challenged the recommended treatment. The power and authority of physicians in decision making was maintained through manipulation of medical information provided to patients and because patients' comments and questions were often blocked or ignored. Requests from patients that challenged physicians' authority lead physicians to change topics to morality. The researcher questioned whether many of the medical decisions were made in the patients' best interests.

In England, Meredith (1993) conducted a qualitative research study of surgeons, nurses, and their patients. He found that patients, in retrospect, were unhappy about the decision making aspects of their interviews with surgeons. Retrospective negative feelings were greater in patients when surgery did not result in cure. Patients with negative feelings thought that they did not have the opportunity to discuss what they had just found out about themselves. They were also unhappy about the lack of specific details that were given.

Surgeons in Meredith's (1993) study recognized that there was an increasing trend of patients to want more information and be more involved in the decision making process, but they were far from enthusiastic about devoting time to this endeavour. Several surgeons were reluctant to share decision making with patients because they believed that patients did not have the knowledge or would become too emotionally upset. The physicians took responsibility for advising their patients about the most appropriate medical treatment for the medical condition. One surgeon stated, "Those insisting that no mastectomy be performed are making their own compromise" (Meredith, 1993). The surgeon spoke pompously about his or her medical knowledge, but was obviously unaware of the current research in breast cancer. Meredith found that when consent forms were signed, no discussion was offered in two thirds of the cases and many patients were not informed of commonly occurring complications. From the nurses' point of view, too many patients did not know what was wrong with them or what the surgical procedure entailed. Sutherland, Lockwood and Till (1990) found that cancer patients have difficulty understanding consent forms. Nurses believed that surgeons should be more rigorous in telling patients the truth to avoid "sowing seeds of anxiety" (Meredith, 1993). When Meredith observed actual physician-patient interactions, patients did not participate in decision making.

From the above studies, it can be concluded that patients usually assume a passive role in treatment decision making. Physician domination of the patient-physician relationship and the manner in which information is shared tends to keep patients passive.

Hypothetical

Levine, Gafni, Markham, and MacFarlane (1992) constructed a bedside visual aid, which they called a decision board, to help physicians transfer information derived from clinical trials about the risks and benefits of adjuvant chemotherapy to elicit node negative breast cancer patients' preferences to have or not to have the treatment. The instrument was found to be highly reliable (kappa = 0.86), acceptable and helpful when it was tested on 37 newly presenting patients with high risk, node-negative breast cancer patients.

Yellen, Cella, and Leslie (1994) examined 244 cancer patients of all ages treated at a tertiary cancer centre. The patients were presented with hypothetical vignettes that varied in terms of stage of disease and treatment toxicity. Patients were asked to choose the treatment given with respect to varying levels of either increasing cure or extending survival. Patients were then given a second set of vignettes with either mild or severe treatments and different probabilities of one year survival. The researchers found that older adults (n = 43) were no different than their younger counterparts when it came to agreeing to chemotherapy for both curative and control purposes. However, they differed in terms of willingness to trade survival for current quality of life.

Mazur and Hickam (1994) found that patients' treatment preferences for long-term versus short-term survival benefits were influenced by the amount of verbal explanation about five year survival graphs that were presented to them. Patients tended to minimize the importance of medium range data unless it was pointed out to them. Mazur and Hickam (1993) found that framing had a effect on patients' preference for one treatment or another. Dolan (1995) found that patients are capable and willing to use the analytic hierarchy process in making treatment decisions.

Llewellyn-Thomas et al. (1995) presented 90 cancer patients with either neutrally, negatively, or positively framed information about entering a chemotherapy clinical trial. The researchers determined that the manner in which the information was framed had no effect on whether or not a patient chose to enter the trial. Framing had no effect on a patient's preferred decision making role.

When given information and some assistance in interpreting it in hypothetical situations, patients make rational treatment decisions. Framing was inconsistent in its effect on decision making.

In Practice

After discussing treatment choices with their physicians and receiving a two page letter explaining two treatment options: hormonal therapy with Zoladex (goserelin acetate) or surgical castration, Stage D prostate cancer patients (n = 159) were given the opportunity to choose their treatment (Cassileth et al.(1989). Most of the patients (78%) selected Zoladex and 22% chose orchiectomy. Three months later, patients and their wives indicated they were satisfied with their choice of treatment and 93% said they would select the same treatment again.

Neufeld, Degner and Dick (1993) provided an intervention strategy that was used in busy oncology clinics to help breast and gynaecologic cancer patients participate in treatment decision making to the extent that they preferred. After ascertaining patients' preferred decision making roles, nurses helped patients formulate questions for the their physicians. Prior to the medical consultation, nurses shared salient information with the physicians. The nurse assumed the role of an active listener throughout the treatment decision making process that took place during the medical consultation and physical examination. If either the patient or the physician appeared not to understand each others questions, the nurse rephrased the question. The intervention strategy was designed to decrease post-decisional regret about the selected treatment.

Leinster (1994) described how breast cancer patients who prefer to participate in treatment decision making were assisted though the decision making process and follow-up period. To clarify points and answer questions, a breast care nurse was present throughout the consultation and afterward. Later, during a home visit, the nurse elicited the patient's final decision about the type of treatment she preferred and gave the patient a contact telephone number. The patients received detailed verbal and written information and emotional support.

It can be concluded that progress in helping patients to assume an active or collaborative role in treatment decision making, when this is the role they prefer, is taking place in some practice settings.

Recommended

Patient participation in the treatment decision making process has been recommended when considerable uncertainty exists relative to the ideal therapy. Examples are: (a) radical prostatectomy, external beam radiation, or watchful waiting initially for localized (stage A or B) prostate cancer (Fleming, Wesson, Albertsen, Barry, and Wennberg, 1993; Montie, 1994); (b) to have or not to have adjuvant chemotherapy for node negative breast cancer patients (Hillner & Smith, 1992); (c) treatment programs for older women with early stage breast cancer (Silliman, Balducci, Goodwin, Holmes & Leventhal, 1993); and (d) splenectomy or medical treatment for advanced agnogenic myeloid metaplasia (Benbassat, Gilon & Penchas, 1990).

Verhoef, Stalpers, Verbeek, Wobbes and van Daal (1991) found that breast conserving treatment yielded a better quality adjusted life expectancy than mastectomy for treatment of stage I and II breast cancer. The researchers suggested that patient preferences should play a major role in treatment decision making in patients who would prefer mastectomy to breast conserving treatment and in patients with a high risk of local recurrence.

Scorpiglione et al. (1995) found that 38% of breast cancer patients in Italy had received inappropriate surgery with more than two thirds attributed to the performance of unnecessary mutilating Halsted mastectomy. Patient participation in treatment decision making was recommended as a method to promote more appropriate surgical care. Allowing patients a greater say in their care was one of ten suggestions that Janigan (1995) made for improving Canada's health care system.

Till et al. (1992) suggested that there is a need to develop standards for the creation, assessment, and communication of evidence to help transfer research results into clinical practice. To illustrate their point, the authors' considered the problems of decision making in circumstances where choice of therapy depends mainly on the patient's preferences. Till et al. suggested that, in such circumstances, the long term goal would be to develop criteria that could be used to foster shared rational decision making.

Patient's and Professional's Role Perceptions

Strull et al. (1984) found that the decisional role perceptions of health professionals (n=50) were incongruent with the perceptions of their hypertensive patients (n=210). While 63% of the patients claimed that they did not participate in decision making, their health professionals reported that patient non-participation in decision making took place in only 20% of the cases. Health professionals thought that patients preferred to participate in 78% of the cases while 53% of the patients indicated that they did not prefer any participation. Overestimation of patients' perceived role occurred 48% of the time and underestimation occurred 6% of the time when professional's responses were paired with their patients' answers.

There is conflicting evidence about patient's perceptions of their enactment of their preferred decision making roles. Sutherland et al. (1989) found that patients' preferred role and the role they preceived they had assumed was not significantly different. However Brody et al. (1989) found that there were no significant interactions between patients' pre-visit role preferences and post-visit role perceptions. Only half of Bilodeau's (1992) breast cancer patients who preferred to have a collaborative decision making role, perceived that they actually assumed it when the decision to have a lumpectomy or mastectomy was made. Blanchard et al. (1988) found that cancer patients who preferred to participate in decision making preceived that they had been involved in the decision making interaction significantly more that the observer noted.

Blanchard et al.'s finding may offer a partial explanation of why studies that used observation to determine decision making behaviour usually found patients to be more passive than in studies that had patients assess their own decision making roles.

It can be concluded that practitioners and patients do not necessarily share the same perceptions of decision making roles that have been enacted. There is conflicting evidence about patient's perceptions of their actual decision making roles and about patients' enactment of their preferred decision making roles.

Barriers and Enhancers of Patient Participation in Decision Making

The effects of patient's preferences for information, information seeking behaviour, and preferred decision making roles; practitioners' partnership building behaviours; the health care delivery system; and patients' knowledge on patients' participation in treatment decision making will be discussed in this section.

Patient Preferences

The previously discussed studies about information preferences and decision making role preferences are relevant to actual decision making roles to the extent that preferences effect actual behaviour. As indicated previously, conflicting results were produced when patients' decisional role preferences were compared to roles that were actually assumed. Sutherland et al. (1989) found that patients who prefer passive decision making roles usually enact their preferred decision making roles. Bilodeau (1992) found that when patients' preferred collaborative decision making role they assumed their preferred decision making role in only 50% of the cases. It would appear that there are barriers preventing enactment of preferred decision making roles when patients want a collaborative role. Preferences interact with situational and intrapersonal factors to determine actual decisional role behaviour.

Information Seeking

Information is a prerequisite for meaningful participation in decision making. Newly diagnosed cancer patients want information about their diagnosis, treatment and prognosis as well as information about the implications of their disease and its treatment on their physical, psychological, family and social well-being (Kochevar, 1994). However, even when patients recognized they had a right to medical information, and demonstrated a desire for information, they were passive about seeking information during the patient-physician interaction (Beisecker, 1988). Beisecker and Beisecker (1990) reported that although patients were desirous of information on a wide range of medical topics, they engaged in few information seeking behaviours when communicating with their physicians.

Beisecker and Beisecker found that information seeking behaviors had little to do with a desire for input into decision making. Instead, they suggested that information seeking was associated with situational variables such as length of interaction, diagnosis, and reason for the visit. They reported that it usually took at least 19 minutes before patients started to engage in information seeking behaviour but the median time for visits was 18 minutes.

Sutherland et al. (1989) found that, in general, the cancer patients in their study had perceived themselves to be active in obtaining information. There was a trend toward increased information seeking among patients who preferred more participation in treatment decision making. However, 63% of the subjects who wanted little or no involvement in decision making also demonstrated high levels of seeking information.

Barsevick and Johnson (1990) studied 36 women who were undergoing colposcopy. The women's information seeking behaviours were influenced by their preferences for information and behaviourial involvement. Information seeking was associated with having confidence but it was not associated with fear, anger or depression.

Steptoe, Sutcliffe, Allen, and Coombes (1991) found that there was generally a high level of satisfaction with information provided about tests, symptoms and treatment in 77 hospitalized cancer patients. The patients who were less anxious and who reported the highest satisfaction with the information they received, tended be the ones who had information avoidant coping styles. They were also less knowledgeable about cancer. It appears that mainly the needs of people who avoid information were being met. Those who used information to cope were less satisfied with the information provided and had greater anxiety. Although the information seekers were more knowledgeable than the information avoiders, it seems that the information seekers needs were not being met as well as the information avoiders.

Deming (1989) examined information seeking and treatment decision making behaviour in 87 cancer patients who chose mastectomy or lumpectomy/radiation. Women with an internal locus of control and moderate anxiety participated actively in the treatment decisions while women with an external locus of control and intense anxiety tended to rely on their physicians and significant others. Internal locus of control correlated with more active information seeking. Anxiety was not associated with decisional behaviour. Surgeon recommendations were followed significantly more by those who chose mastectomy than by those who chose lumpectomy. The choice of mastectomy was associated with a higher fear of recurrence, a lower fear of mutilation, and lower body esteem while the choice of lumpectomy was associated with lower fear of recurrence, higher fear of mutilation, and higher body esteem. The mastectomy and lumpectomy patients did not differ in their levels of anxiety or psychiatric symptoms.

Rakowski et al. (1990) in a telephone survey, found that women were more likely than men to seek information and that more frequent information seeking was associated with favourable responses to several health practices. They proposed that information seeking is a component of personal health practice. Shaw, Wilson and O'Brien (1994) explored the influence of information on the breast biopsy experience. Patients' uncertainty about the possible outcome led to feelings of distress. The major strategy that they used to reduce their distress was to control the amount and type of incoming information.

Manfredi, Czaja, Price, Buis, and Janiszewski (1993) explored information seeking behaviours of 257 cancer patients and their relatives who obtained specific treatment related information from the Cancer Information Service (CIS) and compared them to 262 hospitalized cancer patients. Approximately half of the hospitalized patients had sought information from at least one other source besides their physicians. The hospitalized information seekers were similar to the CIS patients in that they were more likely than their non-information seeking counterparts: (a) to have felt more stressed when they were first diagnosed, (b) to have sought a second opinion, (c) to have been seen at more hospitals and by more physicians, (d) to prefer greater information about and involvement in their treatment plans, and (e) to have been less confident that physicians always have the most current cancer knowledge. The majority of the information seekers were looking for explanatory information about their cancer or treatment. Most wanted the information between the time they were diagnosed and starting treatment. The hospitalized patients that did not seek information had less defined questions and consulted fewer sources; only a few of them received the type of information provided by the CIS, and they were less likely to discuss the information obtained from various sources with their physicians.

Marcus, Woodworth, and Strickland (1993) found that the vast majority of callers to the CIS are female, white, and of middle-class background and that most calls related to cancer treatment issues. The researchers suggested that the CIS can influence behaviour, in particular, information-seeking behaviour. In a meta-analysis of patient-physician communication, Hall, Roter, and Katz (1988) also found that females, whites and people in higher socioeconomic classes seek and receive more information than their counterparts.

It can be concluded that information seeking is an adaptive response to being diagnosed with cancer, patients who prefer to participate in treatment decision making are information seekers, and women tend to seek more information than men. It could be inferred that cancer patients who prefer to participate in treatment decision making but who are not given information or who do not have access to information are thwarted from participating as they would prefer in treatment decision making and from using their preferred coping mechanism, information seeking, in dealing with the cancer experience. In contrast, cancer patients who do not want to participate in treatment decision making and who cope with the cancer experience by avoiding information are usually satisfied with the information given by their physicians.

Partnership Building

Hall et al. (1988) defined partnership building as elevating the patient's status within the provider-patient relationship to increase the likelihood of patient participation. Mutuality in giving and receiving information, establishing a warm caring psychological atmosphere and taking a less controlling role are components of partnership building in the patient-practitioner relationship. Hall et al. found a positive association between partnership building and patient satisfaction. Mutuality depends on the beliefs of the person with the most power in the relationship and the general atmosphere that accompanies the structure in which health care is delivered. Sharing control with the patient requires the provider to expend more effort and time to negotiate and communicate than to maintain the traditional medical model (Northouse & Northouse, 1987).

Caring. The patients of physicians who demonstrated caring actions preferred to participate in decision making (Blanchard et al., 1988). Roberts, Cox, Reintgen, Bailie, & Gibertini (1994) found that breast cancer patients have a better psychological adjustment when physicians use psychotherapeutic techniques during the interview when the cancer diagnosis is disclosed. Patients in the Roberts et al. study indicated that their physicians' caring attitude was more important to them than information giving. The specific surgeon behaviours that facilitated patient adjustment included: expressing empathy, allowing sufficient time for patients to absorb the cancer diagnosis, providing information, and engaging the patient in decision making. Patients in the Blanchard et al. (1988) study who received caring behaviours from their physicians had a greater preference for participating in decision making. Caring behaviours may have a positive effect on patient participation in decision making.

Information giving. In a meta-analysis, Hall et al. (1988) summarized the results of 41 studies that measured provider behaviors in medical encounters. Provider behaviors were grouped according to information giving, questions, competence, partnership building and socio-emotional behaviors. Greater patient satisfaction was correlated to more information given. Correlations between provider behaviors, patient variables and provider background variables were extracted. The meta-analysis indicated that (1) more information was given to female patients and to patients in higher social classes, (2) as patient age increased more information was given, and (3) patient recall and comprehension increased when providers gave more information, asked less questions, elevated the patient's status within the relationship by enlisting more patient input and used more positive talk. Women obtained more information because they asked for more, not because more information is volunteered by doctors (Wallen, Waitzkin & Stoeckle, 1979).

In a review of patient-physician communication, Roter, et al. (1988) found that physicians contribute approximately 60% of the talk during medical encounters. The researchers found that about half of patient interaction time is devoted to information giving, 20% to positive talk, 6% to 7% each to question asking, social conversation, and negative talk, and 10% to partnership building.

Hypertensive patients who had been treated by nurse practitioners or clinical pharmacists reported receiving more information than those cared for by physicians (Strull et al. 1984). Roter et al. (1991) found that female physicians engage in more information giving than male physicians. Street (1991) argued that the amount of medical information provided to patients by their physicians is influenced by patient characteristics and the patient's communication style. Street's analysis of audiovisual recordings revealed that information about diagnosis was associated with the patient's anxiety, education, and question asking. If the patient asked or expressed concern, then information about treatment was given. Partnership building behaviour on the part of the physician that solicited patient concerns, questions and opinions opened the door for patient expressiveness and assertiveness.

Siminoff (1992) examined the provision of information to patients for the purpose of informed consent and concluded that giving patients adequate information usually impacted positively on their psychological and physical well-being.

Borgers et al. (1993) found 58% of 40 cancer patients intended to discuss topics of illness and treatment with their specialists. The researchers suggested that motivating factors for cancer patients to plan a discussion with their specialists were fear, uncertainty, and dissatisfaction with information received. In 22% of the cases, cancer patients did not achieve their planned discussion. In 25% of the cases, achievement of the planned discussion occurred due to the initiative of the specialist or the patient's companion. The researchers concluded that information seeking of cancer outpatients is influenced by:

patients' needs, values and beliefs; unexpected situations; patients' skills; and specialists' and companions' behaviour.

Both nurses and physicians could improve their patient education strategies. When nursing staff provided patient education, Zylinski (1993) found that teaching strategies were restricted to information giving or advice giving that was not always effective and that patients were not actively involved in the learning process. Few physicians provide information aids to accompany the information they provide in spite of the reports that cancer patients have poor recall and comprehension of the information they received (Tattersall et al. 1994). Tattersall et al. determined that most cancer patients prefer a take-home audiotape of their initial consultation with a medical oncologist rather than an individualized summary letter. Hack et al. (1994) found that patients who preferred to collaborate in treatment decision making preferred a summary letter over a tape recording while passive patients preferred either a summary letter or no written information. There was no difference in effect on recall, anxiety or depression between having been given an audiotape or a summary letter (Tattersall et al., 1994). Tattersall et al. found that patients used the learning aids to review the information presented and to share the information with relatives and friends.

Teasdale (1993) suggested that reframing and empowering interventions were better than providing information in a neutral way with no direct attempt to influence the inferences that patients make. It was argued that health professionals rarely offer explanations in a neutral manner. Instead they have biases about what is best for the patient and use information to induce patients to respond accordingly.

Miyaji (1993) observed that physicians use their power to control information through their management of the information giving process. The researcher found that physicians' discourse justified their control over information giving. The study indicated that information about treatment was more readily shared than information about prognosis and that the way physicians control information giving was closely related to their own emotional coping methods, institutional and legal constraints, and power relationships among patients, physicians, and other care-givers.

It can be concluded that care-givers provide information. However, their use of strategies that improve patient recall, comprehension and application often leaves much to be desired. In many instances, information is provided only if patients display a need for it. Unfortunately, patients often do not reveal their desire for information to their care givers. However, giving detailed information to all patients is not indicated because some patients cope by avoiding information. Lantos (1993) pointed out that physicians have routinely withheld information from patients since the time of Hippocrates and that providing patients with truthful information is a relatively new standard.

Beliefs. Leberati et al. (1990) found that the likelihood of Italian physicians' preferences for type of surgery to treat breast cancer was influenced more by their speciality and the extent to which they felt that patients should have a role in treatment decision making than by differences in beliefs about treatment outcomes. Those who believed that patients should have a role in treatment decision making were more likely to offer their patients a choice between lumpectomy or mastectomy. Surgeons and internists were more supportive of traditional radical techniques. The researchers suggested that only ignorance or distrust of results from clinical trials could account for the beliefs of physicians who thought that radical surgery was the sole admissible treatment for breast cancer.

Beisecker et al. (1994) surveyed 67 oncologists and 94 oncology nurses and 288 patients from a women's clinic. The oncologists, nurses, and women all believed that the physician should bear most of the responsibility in making medical decisions. However, the nurses believed that breast cancer patients should have more decision making responsibly than the women believed. The oncologists believed that breast cancer patients should have less responsibility than the women believed. Surgical oncologists advocated more patient involvement in decision making than medical or radiation oncologists.

Beisecker et al. (1994) found that oncologists' gender was not a significant factor associated with beliefs about patient participation in treatment decision making. This finding conflicted with Beisecker and Murden's (1992) finding that male physicians advocated less patient input into medical decision making than did female physicians. Although there is evidence that older patients are treated differently that younger patients (Yellen et al., 1994), Beisecker et al. found that oncologists and nurses reported that their beliefs about including patients in decision making were not affected by patients' ages. Social desirability may have accounted for their responses because it is politically correct to treat patients equally. When Beisecker et al. asked what other information respondents needed for them change their responses about deciding who should take responsibility for treatment decision making, nurses and a small number of oncologists indicated patient's preference for level of involvement in decision making.

Nursing theorists such as King and Orem have hailed the benefits of patients participating in planning their own care and of patients undertaking self-care activities. However, Zylinski (1993) found that postoperative patients have a low expectation of being informed or of participating in their care. Teasdale (1993) noted that in hospital settings, opportunities for patient control are not obvious and that it would be a challenge for nurses to identify situations in which patients could meaningfully exercise control over events.

To conclude, physicians adhere strongly to the belief that they should be the ones who are primarily responsible for making medical decisions. Nurses are stronger advocates for patients being involved in making decisions about their care than patients and physicians. However, not all patients are ready or willing to assume a collaborative role in treatment decision making and the hospital environment may make patients' opportunities to participate in decision making less obvious. It would appear that nurses and patients who prefer a collaborative role in treatment decision making are more inclined to fit into the compensatory model while physicians and passive patients are more inclined to fit the medical model.

Health Care Delivery System

As indicated earlier, Beisecker & Beisecker (1990) noted that consumerist behaviour in patients usually did not begin after the patient and physician interacted for 19 minutes. This is a significant finding since Beisecker and Beisecker found that the median visit lasted 18 minutes. Roter, Lipkin and Korsgaard (1991) found that the average visit to a male physician lasted 20.3 minutes while female physician visits lasted an average of 23.9 minutes.

Busby and Gilchrist (1992) studied the views of 33 consultants, 14 nurses and eight patients to reveal the nature of ward rounds. They found that medical staff dominated the proceedings and other health care professionals had little involvement. Patients received little explanation and had much difficulty understanding the discussions. If this study is representative of most ward rounds then patients are certainly not provided with the type of information they need to participate in treatment decision making and they are not being invited into a partnership relationship about their care.

Meredith (1993) found that the time interval between disclosure and the decision to have surgery was too brief for the patients to have their opinions of the matter considered. He suggested that clinical character of the discourse that had defined the meeting prevented patients from having input into the decision even when there was sufficient time. It would appear that the clinical discourse that Mishler described in 1984, that disallowed the patients' lifeworld to enter the scene, was alive and well. Meredith (1993) found that patients were aware of the time constraints while meeting with their surgeons and were careful not to consume more than their allotted share.

The power of the physician and the environment in which health care is provided can effect patient-practitioner information flow which in turn effects patient participation in medical decision making.

Knowledge

Weeks (1994) suggested that if patients were knowledgeable of the expected outcomes of treatment options and were given the opportunity to have to have complete decisional autonomy, they would receive therapy congruent with their preferences. Few patients want complete autonomy but many prefer shared decision making. If active or collaborative decision making is to be achieved by those who prefer it, patients must inform their care givers about their preferences, and detailed medical information must be provided to patients who prefer it (Weeks, 1994).

Information needs. Mackillop et al. (1988) interviewed 100 cancer outpatients in Kingston, Ontario. All except two patients recognized that they had cancer and 87 were able to correctly identify their type of tumour. Patients' expectations of cure was in agreement with their physicians in only 37 cases. Most patients (n=57) were more optimistic and six patients were more pessimistic than their physicians. Because most patients were unrealistically optimistic about the progress of their disease the researcher felt that the patients were not capable of making appropriate treatment decisions. Serious misunderstanding of patients' perceptions almost always went unrecognized by their physicians. The researchers suggested that some of the patients' misunderstandings may have been the result of too optimistically presented poor prognoses even though an attempt to discuss the disease honestly with the patient had been made. The study indicates that patients' information needs are not being met at a sufficient level to allow participation in decision making.

Derdiarian (1986, 1987a, 1987b) assessed the information needs of 60 cancer patients who had received their diagnosis from one to 18 days previously and were anticipating their initial treatment. A hierarchial pattern of four major categories of information needs were identified (disease > personal > family > social relationships). Information needed in the disease concerns category included: nature, extent and etiology of disease; nature results and consequences of tests; nature, intended and unintended consequences of treatment; facts and implications of prognosis. Information in the category of personal concerns included implication for self, career, modification of future plans, physical functioning, resources to maintain physical and psychological well-being, and how to handle emotional disturbances. Information needs in the family category included how to handle the impact on spouse, children, parents, and siblings. Information needs in the social concerns category included implications for communication, interaction and attainment of assistance related to job/career relationships, special interest groups relationships, leisure group relationships and future relationships. The information needs of patients demonstrated congruency with the harms, threats and resources related to the implications of the diagnosis. The researcher concluded that individuals seek information to appraise harms, threats and resources when encountering harmful or threatening events.

Brandt (1991) developed a instrument to measure the specific learning needs of cancer patients having radiation implant therapy. The relationship of information needs to patients' preference to participate in treatment decision making was not reported. Bilodeau (1992) measured how breast cancer patients prioritized their information needs and found that breast cancer patients who preferred active or collaborative decision making roles had different hierarchial profiles of information needs than patients preferring a passive role. Davidson (1993) determined there was no relationship of information needs of men with prostate cancer to their decision making role preferences. However, Manfredi, Czaja, Buis, and Derk (1993) found that patients with strong information needs preferred to participate in treatment decisions. Manfredi et al. found that most of their subjects needed more information about their illness and treatment than was provided by their physicians.

To assess discharge learning needs, Bubela and Galloway (1990) developed a 50 item forced choice Likert format Patient Learning Needs Scale (PLNS) based on responses from 301 medical-surgical patients in a large teaching hospital in Ontario who were anticipating return home within 72 hours. To improve patient understanding, the items were worded in one direction. Seven subscales (medications, activities of living, feelings related to condition, community and follow-up, treatment and complications, enhancing quality of life, and skin care) which accounted for 56.1% of the variance, were isolated through factor analysis. Bubela and Galloway reported that patients who had malignant diseases and who were female had more information needs than those with benign diseases and who were male. They found also that information needs were positively correlated with length of hospitalization, number of discharge medications, and patients' perception of the influence of the illness on their lives. Using the same tool, Galloway, Bubela, McKibbon, McCay and Ross (1993) found that postoperative lung cancer patients (n=40) expressed a high number of information needs. The information needs that were most frequently identified by pre-discharge postoperative lung cancer patients were: information to help them prevent, recognize and make judgements about complications and information about activity guidelines, incision care, and how their illness would effect their lives.

Specific information needs and how they are measured differs among studies. Information needs at the time of discharge from hospital may become increasingly important to patients who expect to be responsible for self-care activities. It can be concluded that although cancer patients have a high need for information, and the manner in which care givers provide it needs to be improved so that patients comprehend the reality of their situations. Without realistic knowledge, participation in decision making usurped. However, relationship of information needs to decision making role preferences is inconclusive.

Discharge teaching. In a meta-analysis of 102 studies, Devine and Cook (1986) found that psychoeducational interventions have a positive effect on recovery, pain, psychological well-being and satisfaction with care in hospitalized adult surgical patients. To prepare patients to care for themselves after discharge from hospital and to prevent postoperative complications, nurses provide discharge teaching. Decision making can be inherent in self-care activities. Edwards, Broadwater, Bell, Ames & Balch (1988) were able to decrease the average length of hospital stay for mastectomy patients from 10.5 to 4.3 days by teaching patients self-care for their surgical wounds and drains. Patients were discharged with drains in place usually within 72 hours after surgery without any significant changes in rates of complications. Although nothing was mentioned about involving patients in decision making, these patients would have to make decisions while carrying out the their self-care to identify if the wound was healing, if an infection was developing, if the amount and character of drainage was within normal limits in order to know when to request assistance.

Williams et al. (1988) found that mastectomy and hysterectomy patients who received teaching pre-operatively required neither prompting nor assistance in the initiation and completion of ambulation tasks whereas uninstructed patients did not initiate or complete specific tasks in spite of prompting and physical assistance from the nurse. Measures taken one month later indicated that the instructed group was performing self-care activities at home significantly better than and more frequently than the uninstructed group.

It can be concluded that discharge teaching can be effective in helping patients implement self-care activities. However, there is a dearth of data specific to the relationship of discharge teaching to patient participation in decision making.

Comprehension. Cassileth, Volckmar and Goodman (1980) found that 50% of 103 patients receiving radiation therapy, expected to be cured. Of the 57 who were receiving palliative radiotherapy, one third believed they might be cured. Experienced patients perceived themselves to be less knowledgeable than they actually were. Mackillop et al.(1988) found that in 100 cancer patients, 22 misperceived the intent of their therapy, 19 misperceived or were unsure if their disease was localized or metastatic, and 63 misperceived the probability of cure with most being overly optimistic. They found that older and less educated patients were more likely to misconstrue the intent of their treatment. In a meta-analysis, Hall et al. (1988) found that patient recall and understanding increased when more information was given and when care-giver partnership building behaviours were evident.

Denial of information given, confusion over details, and emotional distress all interfere with comprehension. Eden, Black and Emery (1993) suggested that comprehension is improved when information giving sessions are taped, simpler language is used, and complex information is repeated.

Hypotheses

The following hypotheses derived from the literature review will be tested.

1. The majority of patients will prefer passive decision making roles.
2. The preference orders of the majority of patients will be consistent with the existence of a psychological

dimension of keeping, sharing and giving away decision making control.

3. Patients' preferred role in deciding to have surgery will be the same as their preferred role in making the postoperative care decision that they selected as most important in which to participate.

4. Patients preferring collaborative and active decision making roles will be greater in number than those assuming collaborative and active roles.

5. Patients who assume collaborative and active decision making roles will indicate the same amount of need for information about post-discharge self-care management as patients who assume passive decision making roles.

Summary

Participation of the cancer patient in treatment decision making is a complex matter. It depends on intrapersonal, situational and demographic variables such as beliefs about who should be responsible for making the decisions, patients' confidence in their own knowledge, the psychological and physical health status of the patient, the amount of medical information patients obtain and comprehend, and partnership building behaviours of the health care professional. Not all patients are ready to participate in heath care decision making or to receive detailed information about their illness and its treatment. Therefore assessment of decision making preferences and information needs is required.

CHAPTER 3

METHODOLOGY

The methodology chapter includes a description of the design of the study, population, setting, sample, data collection procedures and problems, instruments, and data analysis.

Study Design

A combination of methodologies was used for this descriptive survey. A method of paired comparisons based on L. L. Thurstone's Law of Comparative Judgement (Dunn-Rankin, 1983) was used to rank nine postoperative care decisions. A card sorting procedure was used to determine the order of surgical treatment decision role preferences. Having subjects select one item from a list or an array of items was used to determine their preferred postoperative care decisions, their perceived postoperative care decision making roles, as well as their perceived surgical treatment and postoperative care decision making roles. The Patient Learning Needs Scale, developed by Bubela and Galloway (1990), was used to measure pre-discharge information needs. A semi-structured interview was used to obtain patient's thoughts about their experience in the decision making process and their information needs.

Population and Setting

Newly diagnosed cancer patients who underwent surgical treatment and who were within three days of expected discharge from the St. Boniface General Hospital in Winnipeg, Manitoba were studied. In Manitoba, the 1995 cancer estimates are 5,300 new cases and 2,550 deaths (Canadian Cancer Statistics, 1995). Thirty-eight percent of the cancer cases in Manitoba were treated with surgery alone and 91% had surgery at some point during their illness (Vachon et al, 1990). The number of surgeries performed specifically for newly diagnosed cases was not available. Approximately 25 to 30 cancer operations per week were performed at the St. Boniface General Hospital when the data for this study was collected. The hospital is the second largest teaching hospital in Manitoba and is affiliated with the University of Manitoba.

Sample

The following criteria were used to select a convenience sample of newly diagnosed cancer patients: diagnosed with cancer within the past 180 days; over the age of 18 years; having had either prostatectomy, hysterectomy, mastectomy, breast conserving surgery, gastric or intestinal resection, nephrectomy, pneumonectomy, lobectomy or wedge resection as a treatment for cancer; expected by the nursing staff to be discharged from hospital within three days; and not experiencing severe physical or psychological distress as assessed by the nursing staff. Patients who had significant difficulty with cognition, reading and communicating in English were excluded. Consecutive patients were invited to participate. The projected time frame for data collection was three months or less to collect data from 75 to 100 patients. However, after seven months of data collection, a sample 51 subjects was obtained.

Protection of the Rights of Human Subjects

The approval for this research was obtained from the University of Manitoba Faculty of Nursing Ethical Review Committee (see Appendix A). Every potential subject was presented with a written and verbal explanation of the study. Potential subjects were informed that they were under no obligation to participate in the study, were free to refuse to answer any or all questions at any time after entering the study, and could discontinue participation at any time. A copy of the consent form is presented in Appendix B.

If a subject requested a summary of the results of the study, the name and address of the subject was recorded in a separate notebook which was kept in a locked cabinet. After the summary results were mailed, the notebook was destroyed. Names and addresses were not attached to the information gathered from and about subjects. No personal identification of any kind was used on the data collection materials. Only code numbers were used. Anonymity was therefore ensured.

Procedure to Recruit Patients as Subjects

Access to newly diagnosed cancer patients who had undergone and were recovering from surgery at the St Boniface General Hospital was obtained after ethical approval was obtained. A letter requesting access to the eligible patients at the St. Boniface General Hospital was sent to the Director of Nursing Research (see Appendix C). Application procedures specified by the hospital's Department of Nursing Research were followed. After approval to access to St. Boniface General Hospital was received (see Appendix D), the researcher met with the head nurses to inform them of the study, to answer any questions they might have, to request that they identify and invite all eligible patients to participate in the study, and to arrange methods and times for head nurse-researcher communication. Executive summaries of the study (see Appendix E), consent forms (see Appendix B), and data collection tools (see Appendices F, G, H, I, J and K) were given to the head nurses.

The researcher contacted the nurses in charge of the units by telephone from two to four days per week, depending on the individual arrangements made with each unit, to determine which patients were eligible and willing to be approached by the researcher. The researcher approached the identified patients to obtain their informed consent. Verbal and printed explanations of the purpose of the study and the protocol to be followed were provided. After the consent form was signed, the patient was given the choice of starting data collection procedures immediately or of making an appointment with the researcher to return at a more convenient time to begin data collection.

From August 6, 1991 to March 3, 1992, a total of 102 patients on four surgical wards and one gynaecology ward who met the criteria were identified to the researcher as potential subjects. Data collection was initiated with 55 of them. Of those who did not become subjects, 29 indicated that they did not want to participate after being approached by the nurses. Another seven declined to participate after the researcher requested their informed consent. Eleven patients agreed to participate, however the researcher was unable to meet with them before they were discharged. This occurred when patients were discharged sooner than the nurses expected, or when patients were discharged from hospital immediately after being informed of pathology report results. This did not permit the researcher to meet with the patients to collect data before they were discharged.

Four subjects were deleted from the study. Information had been collected from one postoperative cancer patient who did not fit the criteria of the study. Although the patient had been seeing a physician who had diagnosed her with cancer over a year ago, she was not aware that it had not been "taken care of" at the time it was diagnosed. She was therefore not a newly diagnosed patient. Data on this patient were not used in the analysis. The other three subjects were deleted from the study because only demographic data were obtained before they declined further participation. One of the three subjects was encouraged by his wife not to participate. The other two subjects opted out of the study because they felt that participation in the study interfered with the time they had to see visitors. Deletions reduced the size of the total sample to 51 subjects.

Patient Recruitment Problems

On November 13, 1991 the Director of Surgical Nursing at the hospital informed the researcher that she could no longer collect data from patients who had colostomies because there were three other nurse researchers who were studying ostomy patients. The researcher was informed of three colostomy patients meeting the criteria for inclusion who therefore were not approached for this study. The restriction against interviewing colostomy patients was lifted at the beginning of March, 1992.

Enrolment of subjects was hampered mostly by the length of time it took for pathology reports to be delivered to the wards. If there were no confirmed diagnosis prior to surgery, the pathology report was required to determine if the patient had cancer. On 11 different occasions, one head nurse stated that there was no pathology report on the chart and therefore would not approach patients even though they had undergone bowel resections, mastectomies or partial mastectomies. This happened most often in patients who had partial mastectomies because their hospitalizations were usually very short. After several weeks went by and the head nurse kept informing the researcher that no patients were available that fit the criteria, the researcher requested an explanation for the lack of patients. The head nurse stated that most of the partial mastectomy patients who were cared for on her ward did not have a confirmed diagnosis before they were discharged from the hospital and therefore could not be approached for the study. Three patients who received unfavourable pathology reports were also not asked by the same head nurse or her designate to participate in the study. These patients were assessed by the nurse as too overburdened to participate. Other postoperative cancer patients who were on this ward were described by the nurse as terminal and therefore also not appropriate for inclusion in the study. Only four subjects were accrued from this ward. Nurses were not asked to identify patients who did not agree to participate in the study or who could not be invited to participate because the pathology reports were not available. Therefore the total number of patients who were receiving postoperative care following surgical treatment of cancer was not available.

Visitors who were with the patient at the times when data collection were scheduled made it difficult for the researcher to actually collect data. The researcher had to repeatedly reschedule interviews because many patients preferred having visitors to participating in the study.

Data collection usually took place in the patients' rooms. In most instances a private room for interviewing the patient was not available. When the patient was in a two bed room, the curtain was drawn around the patient's bed to provide a semblance of privacy. If the patient was not in a private room and the patient lounge or conference room was vacant, the patient was given the opportunity to have the data collected there. The time it took to collect data from patients ranged from approximately a half hour to one and a half hours.

Description of Instruments

Preference for Participation in Postoperative Care Decisions

A questionnaire (see Appendix G) was used to determine, from the patient's point of view, the rank order of importance of having his or her opinions included in making nine different postoperative care decisions. The nine postoperative care decisions were presented in 36 unique pairs. Patients were requested to circle one of each pair of postoperative care decisions that was most important to have his or her opinions included during the decision making process. When listening to subjects' verbalizations while they made their selections from the paired postoperative decisions, the researcher was not always certain that the subjects were following the specific instructions. The researcher began to wonder if subjects were making selections based on the importance of the decisions rather than the importance of having their opinions considered. Therefore the researcher included a verbal caution that it was the latter and not the former that should be the basis of their selections.

The questionnaire also requested the patient to select one of the nine postoperative care decisions believed to be the most important in which to participate. If the patient had a more important postoperative care decision in which to participate, a line was provided to write in the decision.

No patient wrote on the line provided. Questions about patient's perception of his or her illness situation and demographic information which is not usually available on the health record, were also asked. Development of the questionnaire is described in Appendix L.

Control Preferences Card Sort

Degner and Sloan (1992) developed a set of five cards (see Appendix I) to illustrate the range of patient-physician treatment decision making relationships. The preference order of patients' surgical treatment decision making roles was determined using the Control Preferences Card Sort described by Degner and Russell (1988)(see Appendix M). The cards were then arrayed before the client to pick the role actually assumed for surgical treatment decision making.

The preferred and actual roles that patients played with regard to their previously selected postoperative care decision in which participation was most important, was determined with the use of five cards with the same illustrations but with altered captions (see Appendix J). The alterations made the cards more relevant to the decisions being studied and to the health care providers with whom discussion of the decisions may have been initiated. The postoperative care decisions under investigation were decisions about the day to day management of the patient after surgery. The word "treatment" was deleted from the cards because patients may not consider day to day management decisions as treatment decisions. Because there is a shared responsibility of physicians and nurses in making many of the postoperative care decisions "doctor" was changed to "nurse or doctor." The five cards were arrayed before patients who were asked to pick the card that most closely approximated their preferred role in making the postoperative care decision in which they had previously picked as most important to have their opinions considered. The patients were then asked to point to the card that best approximated the role that they perceived had actually taken place.

The Patient Learning Needs Scale

The Patient Learning Needs Scale (see Appendix H) was developed by Bubela and Galloway (1990). The 50 item scale had a Cronbach's alpha of 0.95 when it was tested on 301 adults hospitalized in Ontario with medical or surgical illnesses. The instrument is composed of seven subscales: medications, activities of daily living, feelings related to condition, community and follow-up, treatment and complications, enhancing quality of life and skin care. These seven factors accounted for 56.1% of the variance. The authors and the Sunnybrook Health Science Centre copyrighted the questionnaire but allowed it to be used in this study provided that the data collected with the instrument is given to them so that they can further refine the instrument.

Semi-Structured Interviews

Semi-structured interviews with patients (see Appendix K) were used to explore patients' perceptions of nursing actions that facilitated and hindered acquisition of information and achievement of preferred decision making roles. Subjects' verbal responses were written by the researcher.

Demographics

A patient demographic data form (see Appendix F) was used to record gender, age at last birthday, length of time in days since diagnosis was communicated, type and stage of disease, and type of surgical procedure and number of coexisting illnesses. Because the length of time since diagnosis was communicated to the patient is frequently not recorded in the chart, the date on which the patients were informed of the cancer diagnosis was requested in a patient questionnaire. The number of days from the date provided by the subject to the date of data collection was calculated by the researcher as the number of days since diagnosis. Only patients who had preoperative biopsies usually had the specific type and stage of cancer recorded on the chart. Therefore, the "type" of cancer was recorded as the organ which was affected. The outcome of surgery was defined as "clear of cancer" if the pathology report indicated that surgical margins were clear, no involvement of lymph nodes, and there was no evidence on the chart that metastases had occurred. If the surgical margins were not clear, lymph node involvement was evident, or evidence of metastases was noted on the chart, the outcome of surgery was defined as "not clear of cancer". Coexisting illnesses were defined as any chronic condition diagnosed prior to admission and documented in the chart or any condition other than the reason for the surgery that was diagnosed after admission to hospital and was documented in the chart.

Procedure for Data Collection

The researcher telephoned the nurses in charge to ask if any patients who fulfilled the criteria for the study were available on the ward. If there were any, the nurse provided the patients with a written explanation of the study and asked them if they would like to participate. If the patient agreed, the nurse informed the researcher of the date when the patient would be expected to be within three days of discharge from the hospital. The researcher approached the identified patients within three days of their expected discharge from the hospital. At this time, verbal and written explanations of the study were provided by the researcher. If the patient agreed, the consent form was signed and data collection procedures were immediately initiated, or if the patient preferred, data collection was deferred to a more convenient time. When data collection was deferred to a later time, the researcher and the patient made an appointment for data collection at a mutually agreeable time. When the data collection immediately followed the signing of the consent form, the data were collected in the same order that the instruments were described in the previous section. When the data were collected at a later appointment, demographic information was collected from the patient's chart before the other data were collected. The first few questions of the paired comparisons questionnaire and the Patient Learning Needs Scale were completed in the researchers' presence so that the researcher could determine if assistance was needed in interpreting the instructions or in recording the answers. The researcher stayed with the patient or was available to the patient, whichever the patient preferred, when the questionnaires were completed. Some patients who found the position they were in uncomfortable or awkward to circle their answers, requested the researcher to circle their answers for them. When completing the paired comparisons questionnaire, two patients whose first language was not English, requested an interpretation of psychological assistance. The researcher explained that it meant help in coping with emotions or troubled feelings.

Two patients indicated that they were too tired or having pain during the data collection procedure. A second appointment to complete the data collection was accepted by one. The other agreed to fill out the <u>Patient Learning Needs Scale</u> later in the day by herself but did not complete the postoperative care card selection or the interview.

Data Analysis

Conceptual Confirmation Using Unfolding Theory

Degner and Russell (1988) and Degner and Sloan (1992) used unfolding theory to collect data and measure treatment preference orders. A SAS program based on unfolding theory and developed by J. Sloan was used to determine the percentage of subjects who followed the theoretical dimension of keeping, sharing or giving away decision making control. Degner and Russell (1988) described the utilization of unfolding theory to determine the existence of the psychological dimension of treatment decision making control. This researcher utilized their method in the following manner.

To determine the preference orders of patient roles in deciding to have surgery, preference orders provided by patients on the set of five vignettes were analyzed using unfolding theory. Unfolding theory is based on the idea that there is a subjective continuum (x) mediating an individual's choices among a set of given alternatives. Each individual has an ideal point on this subjective continuum, and if this point were picked up and the dimension "folded", the preference order would be represented in the intertwined order of the stimuli on the continuum. Individual or I scales are determined both by the individual's ideal point on the hypothetical continuum and midpoints between stimuli on the J scale. The specific analytic procedure outlined by Coombs (1976) permits the investigator to determine whether a J scale can be unfolded from any particular set of I scales. For a J scale to exist there must be two end points for the scale; this is true if there are two and only two I scales beginning with one vignette and ending with one other such that these two I scales are mirror images of each other (for example, ABCDE and EDCBA). If this criterion is met, the investigator can examine the "fit" between the I scales obtained in the experiment with the hypothesized J scale. For a J scale of five stimuli, a minimum of 13.33% of I scales should fit the model to accept the hypothesis that the underlying psychological dimension exists (McIver & Carmines, 1981).

Ranking of Postoperative Care Decisions and Surgical Treatment Preference Roles Using Thurstone's Law of Paired Comparisons

Paton (1990) laid the groundwork for utilization of Thurstone's Law of Paired Comparisons to obtain a rank ordering of nine stimuli of interest to nurses. This researcher utilized a SAS computer program based on

Thurstone's Law of Paired Comparisons that was designed by J. Sloan to obtain a rank ordering of the nine postoperative care decisions and the five vignettes describing surgical treatment decision roles. The nine postoperative care decisions were ranked according the degree that patients preferred to have their opinions considered when the decisions were made. The nine decisions were judged in every possible combination. The five treatment decision roles were ranked according to patients' preferred level of involvement in decision making when deciding to have surgical treatment for their recently diagnosed cancer. Because the data for decision role preference were collected using unfolding theory, every possible combination of roles was not necessarily judged. Only the order of the preferences were recorded. Thurstone postulated that a set of "n" stimuli possess a varying but unknown degree of an attribute. The attribute of concern in this study was patient autonomy in surgical and postoperative care decisions. A greater preference for having one's opinion considered in the decision making process reflects a greater preference for autonomy.

The ability of the subject to rank one item over another in terms of an attribute is the only restriction on the stimuli (Dunn-Rankin, 1983). The assumption has been made that there are more frequently aroused perceptions among the subjects of the preference for becoming autonomous or of avoiding autonomy in each of the nine postoperative care decisions and of the preference for seeking or avoiding autonomy in each of the five decision making roles. Edwards (1957) pointed out that each stimuli may vary with respect to more than one attribute. The order of the stimuli on a continuum will therefore vary with respect to the attribute being measured.

It was assumed that all subjects had a perception of their preferences for autonomy and that all the stimuli aroused those self perceptions. Thurstone indicated that although subjects may have more or less favourable reactions to being autonomous, there will be a most frequent reaction. Thurstone assumed that reactions to stimuli were normally distributed (Dunn-Rankin, 1983). In normal distributions, the mode, median and mean occupy the same scale positions. As described by Green (1954), the SAS program provided the proportion of times that a stimulus was preferred over the other stimulus. Then the proportions were converted into their normal deviates (z scores). Thurstone's scale was formed by identifying mean values of the z scores. The schematic representation of the paired comparisons of postoperative care decisions is presented in Table 2. The intersection of each column and row represents one of the paired comparisons of postoperative care decisions. The value in each cell corresponds to the number of times that more autonomy in making the postoperative care decision in the column was preferred over the one in the row. The same method of analysis was used to determine the rank order of the five surgical treatment decision making roles.

Table 2. The Fundamental Matrix.

	OBED	FOOD	DRSG	DOSA	TIMA	BLOD	PSYC	ACTV	DISC
OBED									
FOOD									
DRSG									
DOSA									
TIMA									
BLOD									
PSYC									
ACTV									
DISC									

The following definitions apply:

OBED: When I should get out of bed for the first time after surgery
FOOD: Which foods should be served to me
DRSG: When my dressing should be changed
DOSA: How strong a dose of pain medication I should receive
TIMA: What time my pain medication should be given to me
BLOD: If I should had a blood transfusion
PSYC: If I should receive assistance in dealing with the psychological impact of my illness
ACTV: What activities I should do and avoid doing when I go home
DISC: What day I should be discharged from the hospital

Comparison of Thurstone Scale Rankings Between Groups

Before differences between groups could be determined, computations of the mean z scores of each stimulus were carried out according to the method described by Green (1954). The stimulus with the lowest mean z score of the set was assigned the value of 0. The remaining stimuli scale values were determined by finding their distance from the stimulus with the arbitrarily assigned value of 0.

Comparison of scale values between various groups of subjects was calculated by hand using the pooled t tests described by Shott (1990). Differences in preferences for autonomy in the nine postoperative care decisions were determined according to gender, age, education, place of residence, perception of being cured, coexisting illnesses and decision role category. The same type of calculations were used to determine differences in preferred surgical treatment role categories according to gender, age, education, place of residence, perception of being cured and coexisting illnesses. Scale graphs illustrating the differences and similarities between the groups being compared were drawn by a computer program designed by J. Sloan.

Differences Between Decision Role Categories

The same categories of decision role preferences that were used by Degner and Sloan (1992) were utilized in this study. Figure 3 displays the manner in which the role categories were created. Determining differences in the number of subjects who preferred and who assumed active, collaborative or passive roles in surgical treatment and postoperative care decisions was attempted using Chi square. The small sample size of "active" subjects required the collapsing of "active" and "collaborative" subjects into one category. After active and collaborative categories were collapsed, Chi square was used to determine the differences between preferred surgical treatment and preferred postoperative care decision making role categories, between assumed surgical treatment and assumed post operative care role categories, between preferred surgical treatment and assumed surgical treatment roles categories and between preferred postoperative care and assumed postoperative role categories.

Determination of Relationship of Information Needs with Decision Role Categories

The SAS statistical program was used to calculate each subject's the score on The Patients Learning Needs Scale and determined if there was a relationship between self-perceived information needs and decision role categories. The plot of the total learning needs scores did not result in a normal distribution. Therefore a nonparametric chi square approximation test, the Kruskal-Wallis Test, was utilized.

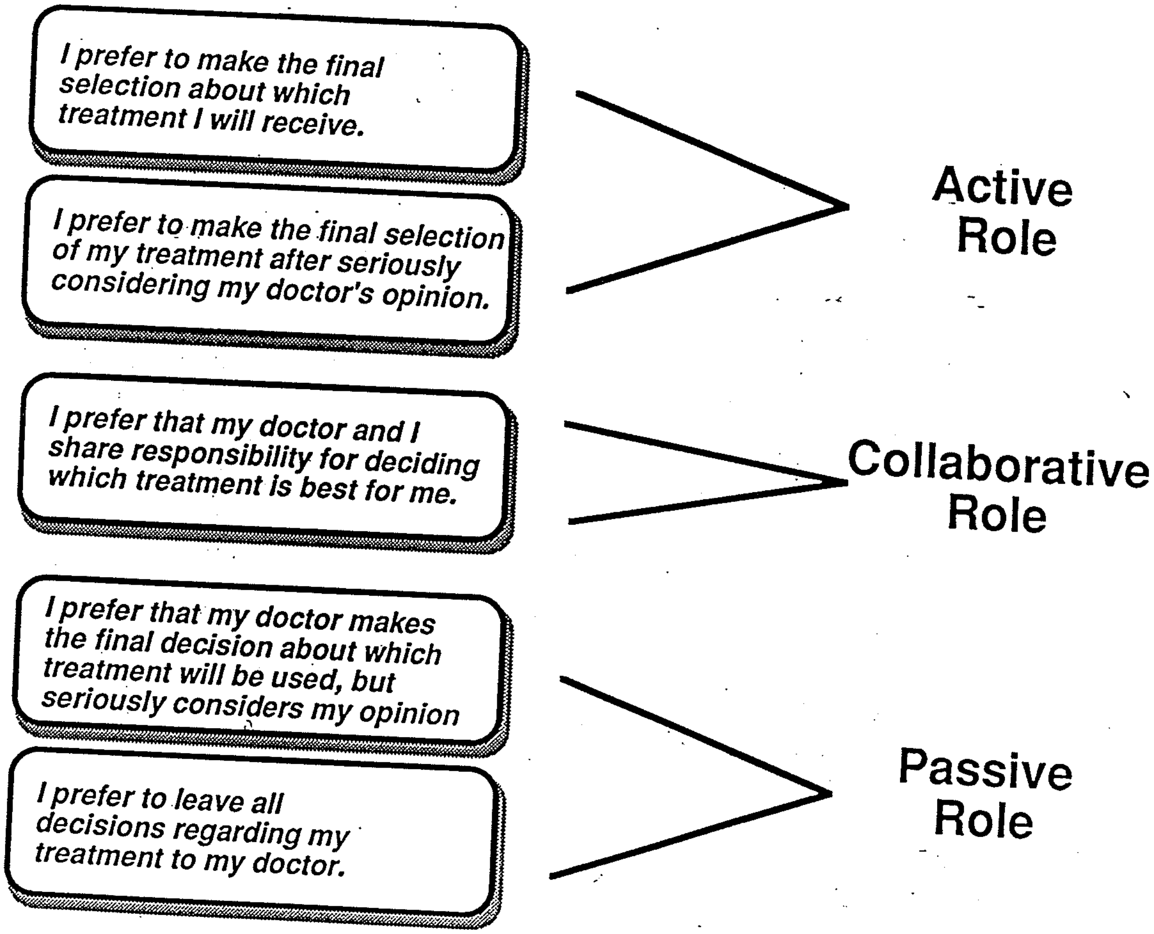


Figure 3. Decision Role Categories (Adapted from "Patient Participation in Treatment Decision Making" by L. Degner, 1992 (September) Axon, p.13.

Summary

This chapter outlined the methods used to study preferred and assumed decision making roles, the rank order of postoperative care decisions in which patients prefer to participate, and the amount of patient perceived learning needs. Thurstone's Law of Comparative Judgement, Unfolding Theory, Chi square, Kruskal-Wallis and pooled t tests were used to analyze the data.

CHAPTER 4

RESULTS

The results of this pilot study will be presented to demonstrate the researcher's process in interpreting the data. First, the characteristics of the subjects are described. Then the results related to postoperative care decisions, preferred and actual decision making roles, and information needs will be addressed separately. This will be followed by a presentation of the interrelationships among the variables.

Subjects

Characteristics

The sample consisted of 22(43.1%) males and 29(56.9%) females between the ages of 30 and 85 years. The median age was 64 and the mean was 61.57 with a standard deviation of 13.36. Subjects living in Winnipeg comprised 66.7 percent of the sample. The remaining subjects were from other parts of Manitoba. Table 3 indicates the level of education of the subjects.

Table 3. Level of education of subjects (n=51).

Grade 9 or less	13(25.0%)
Some High School	8(15.4%)
High School Graduate	10(19.2%)
Trades Certificate or Diploma	11(21.2%)
Some University	6(11.5%)
University Graduate	4(7.7%)

Days since being informed of the cancer diagnosis ranged from 4 to 136. The median number of days was 30 and the mean was 38.04 with a standard deviation of 34.13. Seventy-five percent of the subjects were within 49 days of being informed of their cancer diagnosis.

Patients had from zero to six coexisting illnesses. The mean number of coexisting illnesses was 1.73 with a standard deviation of 1.42. Frequency tabulations of the coexisting illnesses are indicated in Table 4.

Table 4. Frequency of coexisting illnesses in subjects.

Number	Frequency	Percent
0	12	23.5
1	10	19.6
2	18	35.3
3	5	9.8
4	4	7.8
5	1	2.0
6	1	2.0

The patients in the sample had a variety of types of cancer and surgery. Patients with cancer of the prostate (n=14) had radical prostatectomies with pelvic node dissections. Of the 15 patients with breast cancer, one underwent a simple mastectomy, two had lumpectomies and 12 had modified radical mastectomies. The four patients with cancer of the lung had wedge resections. Seven patients were diagnosed with gastrointestinal tract cancer: three had abdominal perineal resections and colostomies, three had low anterior resections and one had a hemicolectomy. Ten patients had hysterectomies; five were diagnosed with cancer of the cervix, two had ovarian cancer, two had endometrial adenocarcinoma, and one had uterine sarcoma. Six of the patients who had hysterectomies also underwent bilateral salpingo-oophorectomies. One patient with ovarian cancer had a bilateral oophorectomy in November 1991 at another hospital. She stated that she was brought in for a staging operation because her pathology report from the oophorectomy revealed that she had cancer. This patient had her uterus removed several years ago to treat menorrhagia. Although she did not have her hysterectomy recently, the researcher felt justified in including her in the sample because a hysterectomy would have been recommended had it not been done before. This patient's results have been included with those patients who had hysterectomies.

The diagnosis of cancer was confirmed by biopsy prior to surgery in 40(78.4%) cases. Of the 23 (45.1% of the total) pathology reports of tissues removed during surgery that were available on the date of data collection, 14 (60.87% of the 23) indicated no evidence of lymph node involvement, margins of the excised tissue were clear of cancer and no evidence in the chart indicated that the disease had spread; 9 (39.13% of the 23) indicated lymph node involvement or intrusion of cancer at the margins of the excised tissue. The patient who had the staging operation had a pathology report which indicated that she had no lymph node involvement and there was no evidence of cancer in the tissue samples and washings. Her results were therefore classified with those who were clear of cancer. The pathology reports of 28(54.9%) patients were not available on the ward on the date of data collection. Therefore no calculations were carried out to determine the effect of disease stage.

Patient Perception of Surgical Outcome

Patient perception about the outcome of surgery compared to the results of the pathology reports is illustrated in Table 5. In 29(56.86%) patients, perception of surgical outcome concurred with pathology report results. In 10(19.61%) instances, patient perception of being cured concurred with the pathology reports indicating no evidence of cancer cells at the excised tissue margins nor in the excised lymph cells. Patient perception of being cured when pathology reports indicated cancer cells were present in the lymph nodes or at the margins of the excised tissue or when there was no pathology report occurred in 12(23.53%) instances. Only one (1.96%) of the nine patients whose pathology report indicated evidence of spread of the disease, acknowledged that the disease was not cured.

Table 5. Perception of outcome compared to actual outcome.

Patient Perception	Pathology Report			Total
	Clear	Not Clear	No Report	
cured	10	3	9	22
not cured	0	1	1	2
unsure	4	5	18	27
Total	14	9	28	51

Patients volunteered the following reasons for their selection of "cured" on the questionnaire: "The doctor told me that all went well during surgery." "I'm recovering to my doctors satisfaction, so all the cancer must have been removed." Several patients for whom no pathology report was available on the ward, commented that they had been told by their doctors that all the cancer was removed during surgery. One patient vented his anger about having been told that all the cancer was removed and then later being told that this was not the case after the pathology report results became available. This patient recorded that he had been cured stating that he could not put a check mark beside "not cured". His remarks vacillated between anger and denial when speaking about his disease. Intellectually he seemed to understand that he had not been cured, but emotionally he had not accepted the information. Another patient said she checked off "cured" even though her pathology report had not come back, because she felt that the response she wrote might influence her actual outcome.

Of the 27 patients who responded that they were "not sure" about the surgical outcome, 23(85.19%) reflected an accurate picture of reality. Pathology reports of 18 of these patients had not yet arrived on the ward. Four had pathology reports indicating that no evidence of cancer had been found at the margins. Even when a pathology report indicates clear margins and no evidence of cancer in the examined lymph nodes, there is a possibility of cancer cells remaining in the body. Therefore, when pathology reports indicate no evidence of cancer in the excised tissue, remaining unsure about being cured is appropriate.

Postoperative Care Decisions

Rank Order of Postoperative Care Decisions

The rank order of importance, from the patient's perspective, of participating in nine postoperative care decisions was determined using Thurstone's Theory of Comparative Judgement. The nine postoperative care decisions that were ranked were: When I should get out of bed for the first time after surgery (OBED). Which foods should be served to me (FOOD). When my dressing should be changed (DRSG). How strong a dose of pain medication I should receive (DOSA). What time my pain medication should be given (TIMA). If I should have a blood transfusion (BLOD). If I should receive assistance in dealing with the psychological impact of my illness and surgery (PSYC). What activities I should do and avoid doing when I go home (ACTV). What day I should be discharged from the hospital (DISC).

Patients were asked to choose one from each pair of postoperative care decisions in which they believed their opinions were most important to be included in the decision making process. The proportion of times the postoperative care decisions listed across the rows of the matrix was favoured over the postoperative care decisions listed down the columns is illustrated in Table 6. A matrix of normal deviates of the proportions rounded down to two decimal points are presented in Table 7. The means of normal deviates indicate the relative scale value for each of the nine postoperative care decisions (see Figure 4). The unit of measurement is one standard deviation of perceived difference between stimuli (Hays, 1967). The variability within the z score matrix is depicted in Figure 5. The decision with the lowest mean value z score is ranked first in importance for participation in decision making. The means of the z scores of the nine stimuli indicate their distance from zero on a normal curve. The grand mean of the nine z scores should be zero (Hays, 1967). Because there was missing data, the grand mean, calculated prior to rounding down to three decimal points, was -0.006678.

Table 6. Proportions matrix of postoperative care decisions.

	OBED	FOOD	DRSG	DOSA	TIMA	BLOD	PSYC	ACTV	DISC
[a]OBED	0	0.60	0.71	0.52	0.46	0.36	0.33	0.26	0.74
[b]FOOD	0.40	0	0.50	0.32	0.40	0.46	0.40	0.34	0.55
[c]DRSG	0.29	0.50	0	0.31	0.28	0.51	0.31	0.26	0.58
[d]DOSA	0.48	0.68	0.69	0	0.65	0.56	0.44	0.30	0.63
[e]TIMA	0.54	0.60	0.72	0.35	0	0.50	0.42	0.30	0.66
[f]BLOD	0.64	0.54	0.49	0.44	0.50	0	0.32	0.44	0.61
[g]PSYC	0.67	0.60	0.69	0.56	0.58	0.68	0	0.40	0.60
[h]ACTV	0.74	0.66	0.74	0.70	0.70	0.56	0.60	0	0.80
[i]DISC	0.26	0.45	0.42	0.37	0.34	0.39	0.40	0.20	0
MEAN	0.53	0.42	0.40	0.59	0.52	0.56	0.61	0.68	0.39

[a] When I should get out of bed for the first time after surgery.

[b] Which foods should be served to me.

[c] When my dressing should be changed.

[d] How strong a dose of pain medication I should receive.

[e] What time my pain medication should be given.

[f] If I should have a blood transfusion.

[g] If I should receive assistance in dealing with the psychological impact of my illness and surgery.

[h] What activities I should do and avoid doing when I go home.

[i] What day I should be discharged from the hospital.

Table 7. Z score matrix of postoperative care decisions.

	OBED	FOOD	DRSG	DOSA	TIMA	BLOD	PSYC	ACTV	DISC
[a]OBED	0.00	0.25	0.52	0.05	-0.10	-0.36	-0.47	-0.64	0.64
[b]FOOD	-0.25	0.00	0.00	-0.47	-0.25	-0.10	-0.25	-0.41	0.10
[c]DRSG	-0.58	0.00	0.00	-0.52	-0.58	0.00	-0.52	-0.64	0.20
[d]DOSA	-0.05	0.47	0.47	0.00	0.36	0.15	-0.15	-0.52	0.31
[e]TIMA	0.10	0.25	0.58	-0.41	0.00	0.00	-0.20	-0.52	0.41
[f]BLOD	0.39	0.10	-0.05	-0.15	0.00	0.00	-0.47	-0.15	0.25
[g]PSYC	0.36	0.25	0.47	0.15	0.20	0.47	0.00	-0.25	0.25
[h]ACTV	0.64	0.41	0.64	0.52	0.52	0.15	0.25	0.00	0.84
[i]DISC	-0.64	-0.15	-0.20	-0.36	-0.41	-0.31	-0.25	-0.84	0.00
MEAN	-0.01	0.18	0.27	-0.13	-0.03	0.00	-0.23	-0.44	0.34

[a] When I should get out of bed for the first time after surgery.

[b] Which foods should be served to me.

[c] When my dressing should be changed.

[d] How strong a dose of pain medication I should receive.

[e] What time my pain medication should be given.

[f] If I should have a blood transfusion.

[g] If I should receive assistance in dealing with the psychological impact of my illness and surgery.

[h] What activities I should do and avoid doing when I go home.

[i] What day I should be discharged from the hospital.

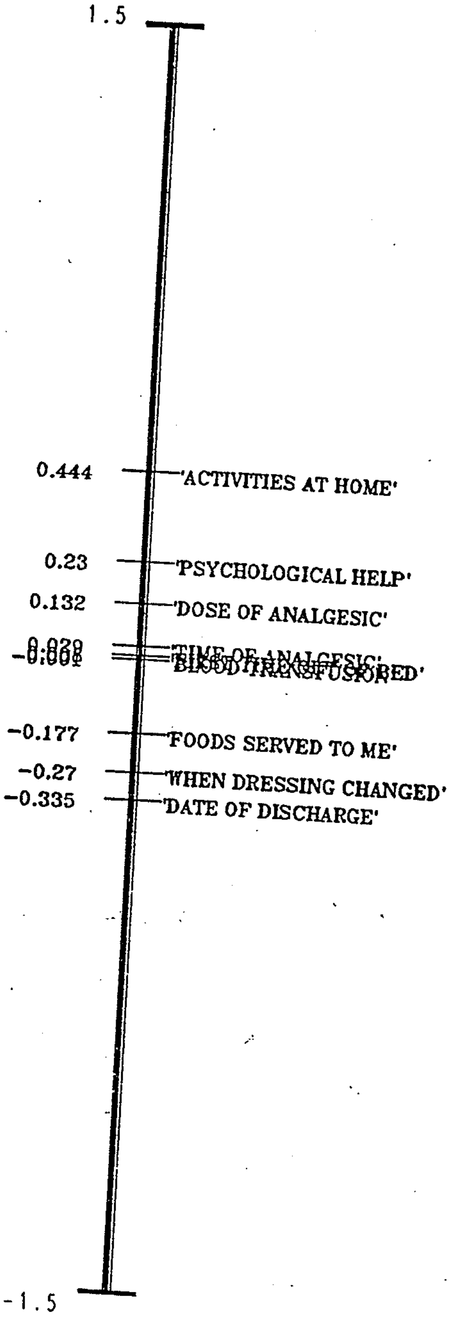


Figure 4. Ranking of patients' (n=50) preferences for participation in nine postoperative care decisions using Thurstone's Law of Comparative Judgements.

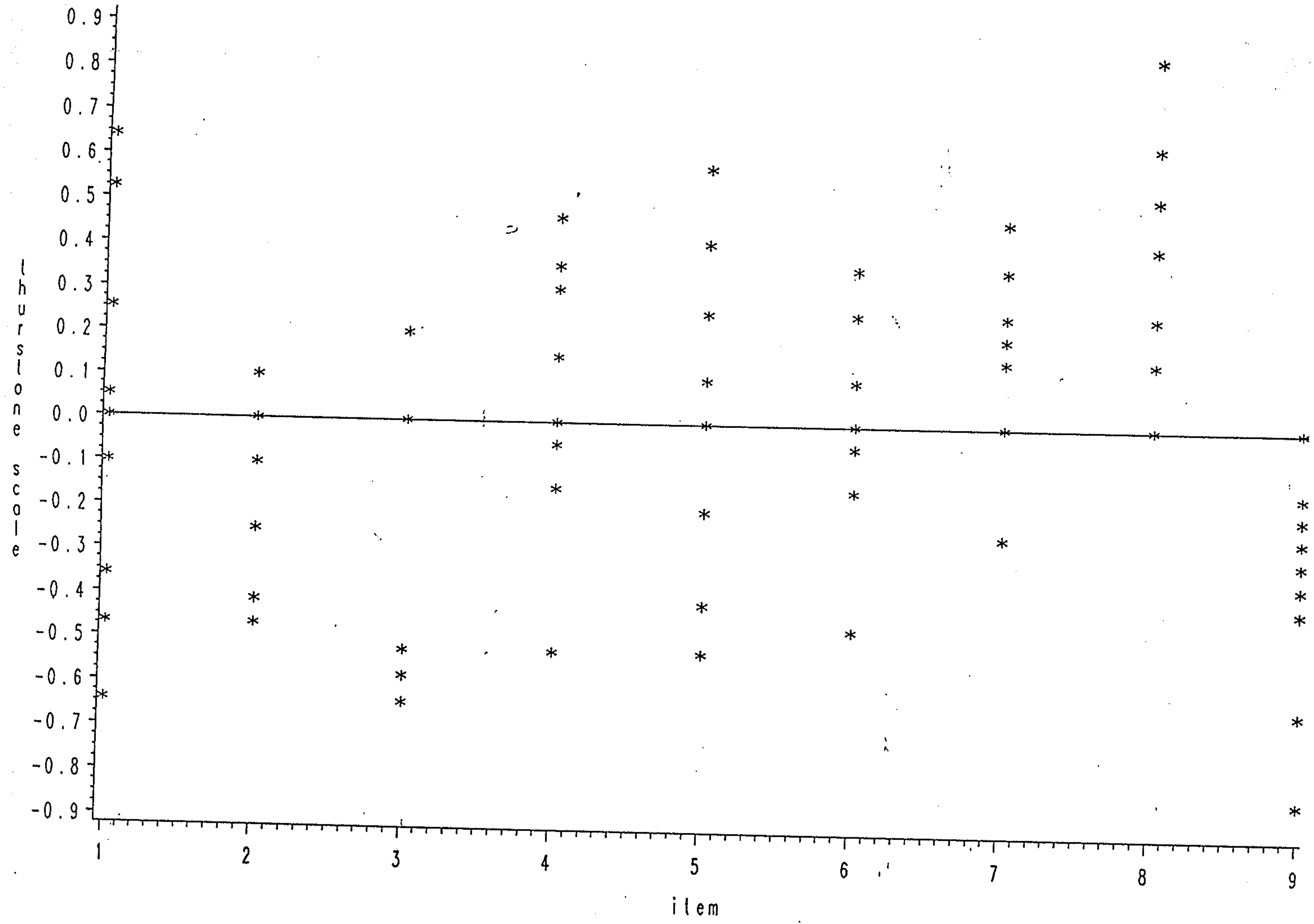


Figure 5. Z score plot of patients' (n=50) preferences for participation in nine postoperative care decisions using Thurstone's Law of Comparative Judgements.

Figure 4 illustrates the positions of the mean z scores in relation to each other. The axial rotation was turned so that the more favourably rated postoperative care decisions are at the upper part of the scale and have higher scores. Decisions related to home activities, psychological help and analgesic dosage were rated most favourably; decisions related to food, dressing changes and discharge from hospital were rated least favourably. Decisions about when analgesics should be given, when to get out of bed after surgery and if blood transfusions should be given were rated neutrally and so closely together that the printing overlaps indicating almost no perceived differentiation of the degree of importance of participating in these postoperative care decisions. The distance from zero indicates the strength of the opinions of the raters. The neutrally rated postoperative care decisions were at zero and the other six decisions were relatively close to zero. None of the decisions exceeded a z score of 1.0 or -1.0. The span of the z scores was 0.779. Therefore the strength of opinions about the importance of participating in all the postoperative care decisions was relatively weak.

Consistency of Raters

The number of circular triads made by a subject indicates the degree of rating consistency of that subject. Kendall's coefficient of consistency, zeta, was used to determine if a rater was consistent with him or herself in answering the questionnaire. When using Kendall's zeta, a subject rating nine stimuli is said to be inconsistent if he or she has made more than 27.2445 circular triads. The statistical program indicated that subject number 46 had 45 circular triads. This occurred because he answered only 16 of the 36 paired comparisons. Therefore the paired comparisons section of his questionnaire was deleted from the analysis. After the deletion, all 50 subjects were deemed consistent by Kendall's zeta. When the 50 subjects rated the nine items, the number of circular triads ranged from 0 ($p = 0.99995$) to 23 ($p = 0.38675$), the median was 7, the mean was 7.56 with a standard deviation of 6.41 and the mean p value of Kendall's zeta was 0.951. Seven subjects did not make any circular triads. Twenty-five percent of the subjects had two or less circular triads. Eight (16%) subjects had 15 or more circular triads. The p values of Kendall's zeta for these eight subjects were less than the mean p value. Despite a lack of perfection, the subjects showed a significant degree of consistency in their judgments. The p values indicated that all 50 subjects were not making their judgments at random.

Edwards (1957) described a formula, $(n^3-n)/24$, to determine the maximum number of triads that can occur for an odd number of stimuli. Using this formula, the maximum number of triads for nine stimuli is 30. However, the statistical program demonstrated it is possible to have 84 circular triads when nine stimuli are compared. Determining consistency of raters using Edward's formula is therefore not a valid test. Of the possible 84 triads of decisions, 81 were made. The three trios of decisions free of circular triads were: dressing change-analgesic time-discharge date (DRSG-TIMA-DISC), analgesic dose-analgesic time-blood transfusion (DOSA-TIMA-BLOD) and analgesic dose-blood transfusion-psychological help (DOSA-BLOD-PSYC).

The frequency with which an item was involved in a circular triad may have been an indication of uncertainty in rating that item. The more often that items are involved in circular triads, the more uncertain subjects may have been in rating the items. The following numbers indicate the frequency of times that individual postoperative care decisions were involved in circular triads: analgesic dosage, 141; first time out of bed, 139; discharge from hospital, 131; activities at home, 131; analgesic time, 113; food, 112; dressing, 107; psychological help, 99; blood transfusion, 92.

<u>Agreement Among Raters</u>

Kendall's coefficient of agreement, which determines the degree to which raters agreed with each other, operates with the following hypotheses.

Ho: Raters' choices were made at random (Rho = 0)

Ha: Raters' choices not made at random (Rho > 0)

Calculated for a sample of 50 subjects each rating nine postoperative decisions, the coefficient of agreement, Rho, was 0.0703. This small number indicates that there is considerable departure from complete agreement. Since it is a positive number, it indicates that there is a certain amount of agreement among the raters. The associated Chi square test statistic of 167.53125 had 38.28125 degrees of freedom and a probability valve of <0.0000001 indicating statistical significance. Raters choices were not made at random.

The rank order of the postoperative care decisions of the 50 subjects determined by Thurstone's Theory is listed below.

1. ACTV: What activities I should do and avoid doing when I go home.
2. PSYC: If I should receive assistance in dealing with the psychological impact of my illness and surgery.
3. DOSA: How strong a dose of pain medication I should receive.
4. TIMA: What time my pain medication should be given.
5. OBED: When I should get out of bed for the first time after surgery.
6. BLOD: If I should have a blood transfusion.
7. FOOD: Which foods should be served to me.
8. DRSG: When my dressing should be changed.
9 DISC: What day I should be discharged from the hospital.

Factors Affecting Postoperative Care Decision Rankings

To determine differences in ranking of postoperative care decisions in patients classified according to gender, age, educational level, residence, existence of coexisting illnesses and perceived results of surgery, pooled two tailed t tests were calculated by hand. The procedure described by Green (1954) was used. Z scores were arranged in hierarchial order. The first ranking z score was arbitrarily assigned the value of 0. The remaining scores were determined by calculating their distances from 0. Tables of the z scores of are in Appendix N.

Gender

Men and women demonstrated significant differences in their opinions about the importance of participating in postoperative care decisions. Women (n=29) wanted more input into postoperative decisions regarding dosage of analgesics ($p<0.005$), psychological assistance ($p<0.01$) and less input into decisions about food ($p<0.001$) and blood transfusions ($<p<0.02$) than men (n=21). The span of z scores was 0.776 in men and 0.910 in women. The first ranked postoperative care decision of both men and women was "What activities I should do and avoid doing when I go home." Figure 6 depicts the differences and similarities between men and women.

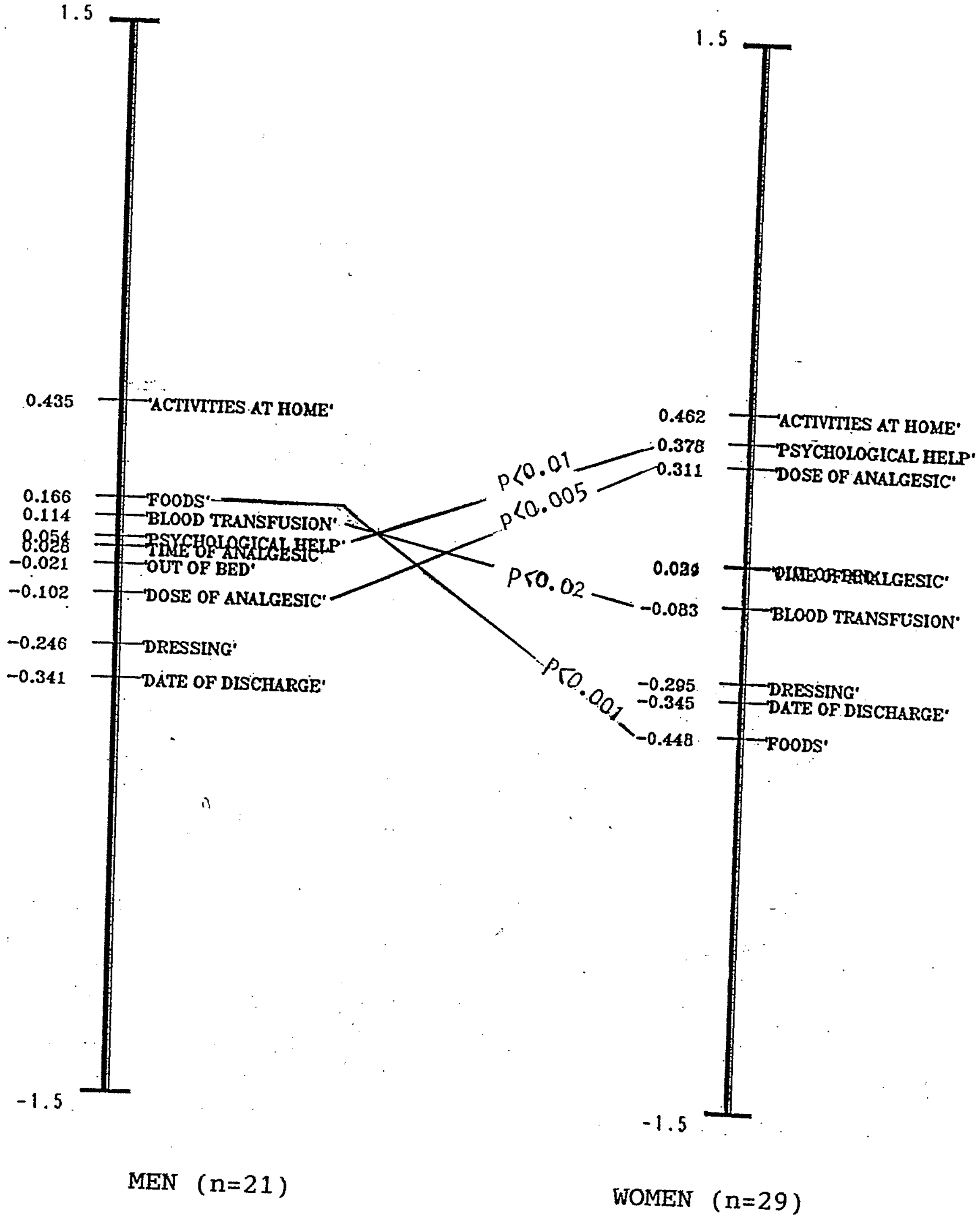


Figure 6. Comparison of men's and women's rankings of preferences for participation in nine postoperative care decisions using Thurstone Law of Comparative Judgement.

Age

Significant differences between younger and older patients' opinions were revealed. Patients under 65 years (n=27) wanted more input into decisions about blood transfusions ($p<0.03$) and psychological assistance ($p<0.04$) and less input into decisions about dressing changes ($p<0.001$), time analgesics are administered ($p<0.001$) and date of discharge ($p<0.001$) than patients 65 years and older (n=23). The span of z scores was 0.981 for patients who were less than 65 years and 0.658 for patients who were 65 years and older. The first ranked postoperative care decision of both younger and older patients was "What activities I should do and avoid doing when I go home." Figure 7 depicts the differences and similarities between younger and older patients.

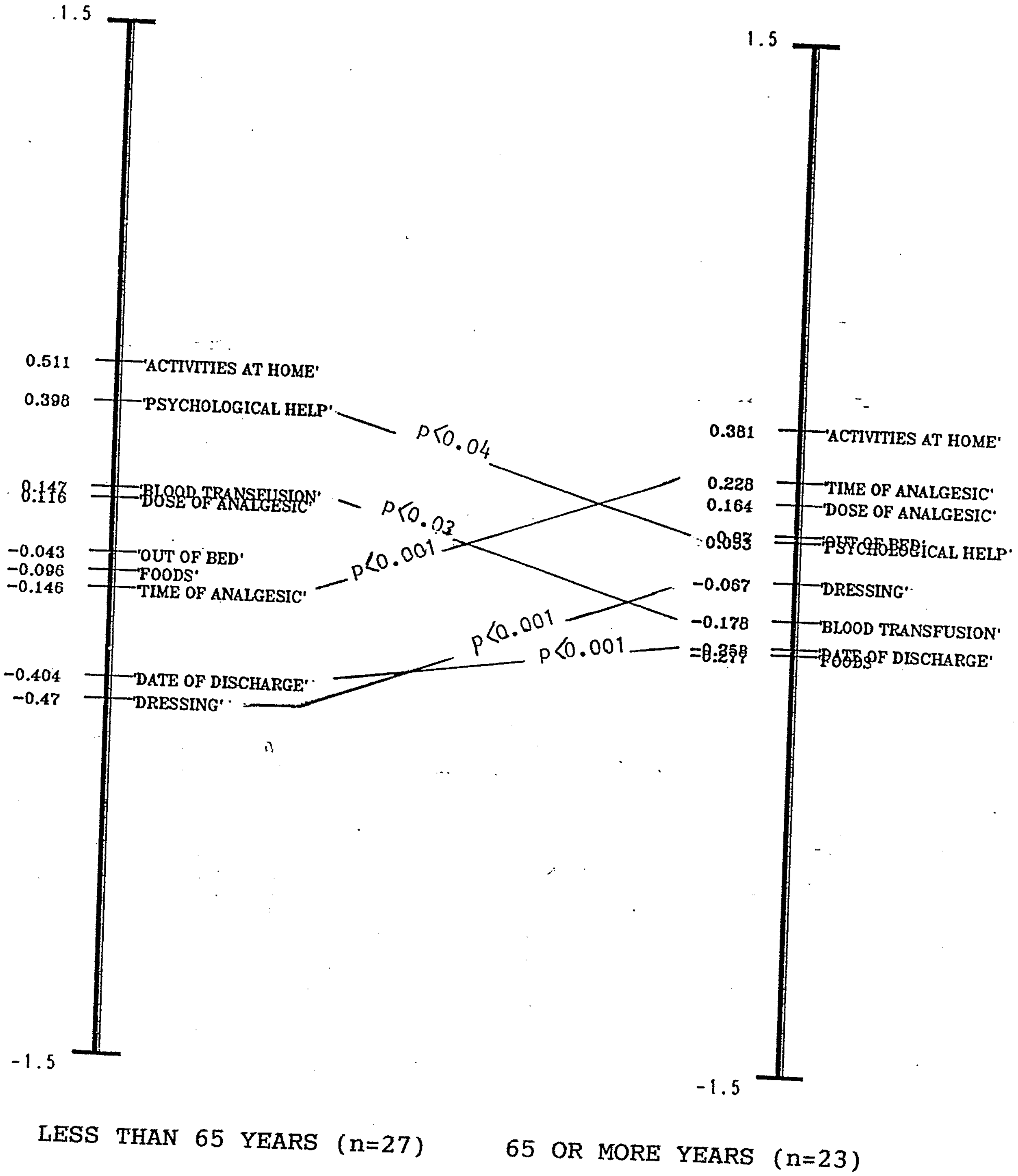


Figure 7. Comparison of younger and older patients' rankings of nine postoperative care decisions using Thurstone Law of Comparative Judgement.

Residence

Whether or not patients resided in Winnipeg had significant effects on their views (see Figure 8). Patients residing outside of Winnipeg (n=17) wanted more input into decisions regarding analgesic dosage ($p<0.005$), time analgesics are administered ($p<0.005$), blood transfusions ($p<0.001$), and date of discharge ($p<0.001$) and less input into decisions regarding dressing changes ($p<0.05$) than patients residing in Winnipeg. The first ranked postoperative care decision of both patients who resided in Winnipeg and patients who did not reside in Winnipeg was "What activities I should do and avoid doing when I go home." The span of z scores was 0.938 in patients who resided in Winnipeg and 0.953 who resided outside of Winnipeg.

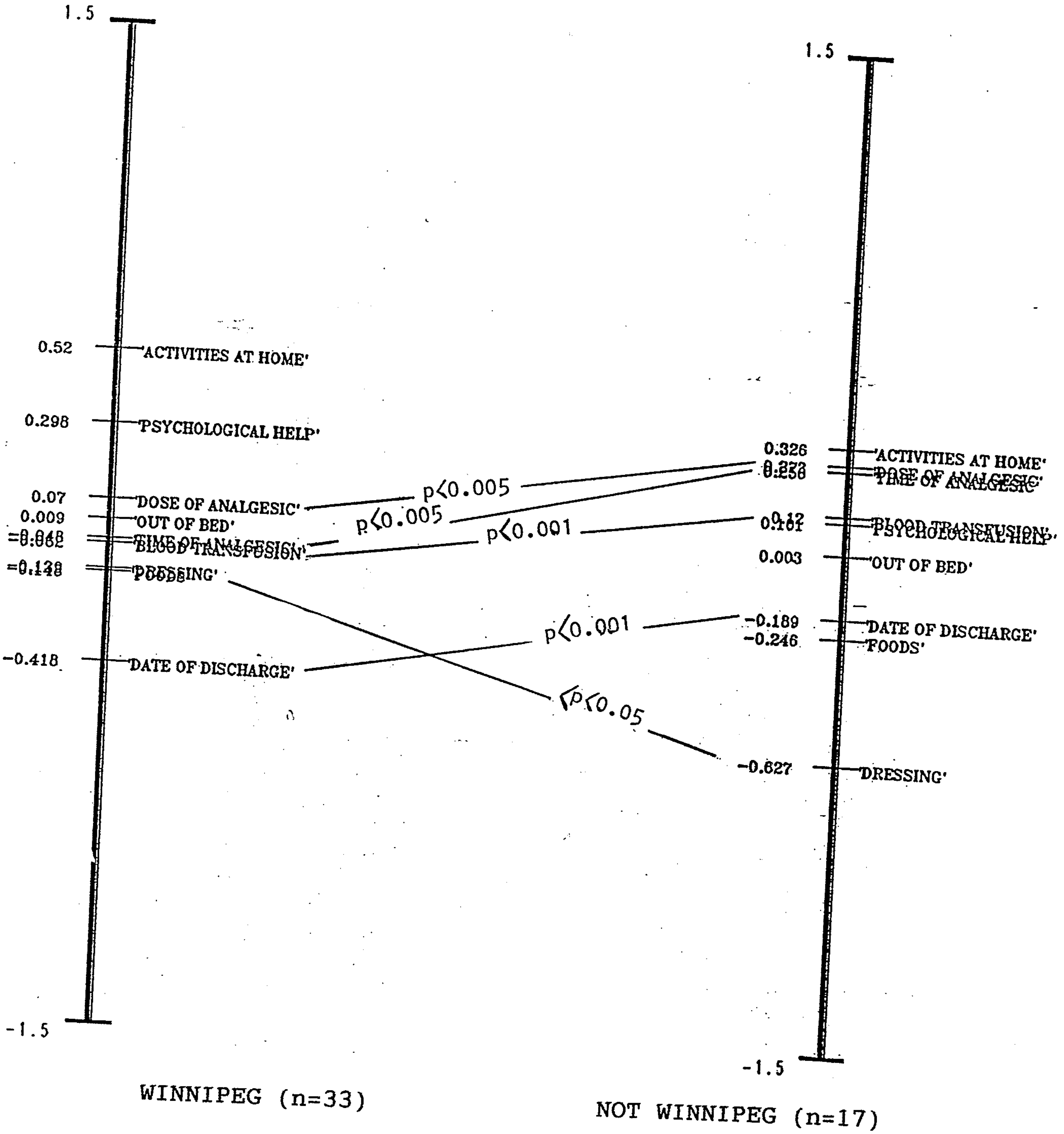


Figure 8. Comparison of patients' rankings of nine postoperative care decisions using Thurstone's Law of Comparative Judgement according to place of residence.

Education

The level of formal education had significant effects on patients' views. Patients who had high school graduation or more education (n=30) wanted less input into decisions regarding dressing changes ($p<0.005$), time analgesics are administered ($p<0.02$) and date of discharge ($p<0.01$) than those with less education (n=20). Patients who did not graduate from high school wanted less input into decisions regarding blood transfusions ($p<0.001$) than those with more education. The first ranked postoperative care decision of both patients with a high school diploma or less education and patients with more than high school education was "What activities I should do and avoid doing when I go home." The span of z scores was 0.881 in patients with more education and 0.657 in patients with less education. Figure 9 depicts the differences and similarities between education levels.

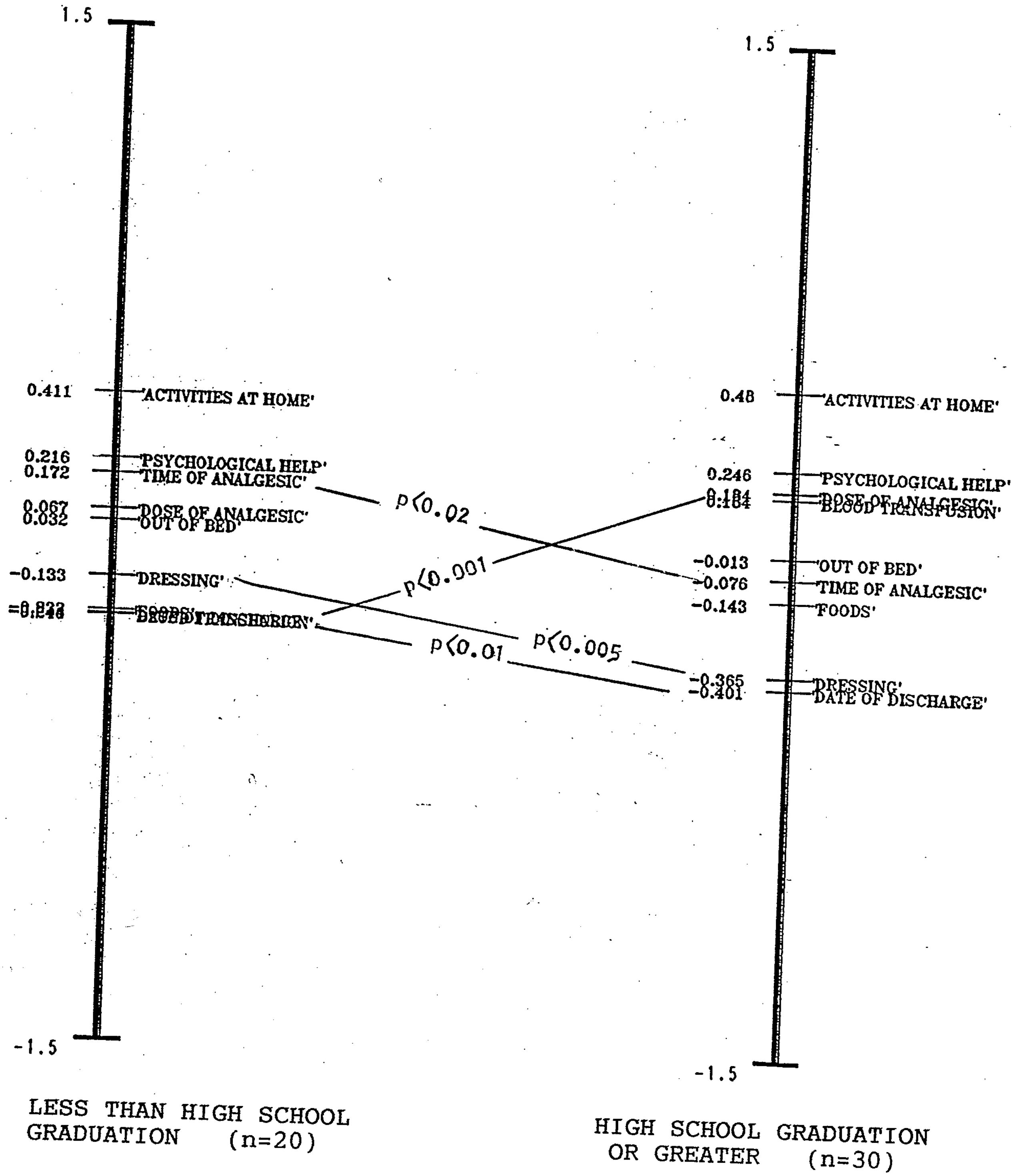
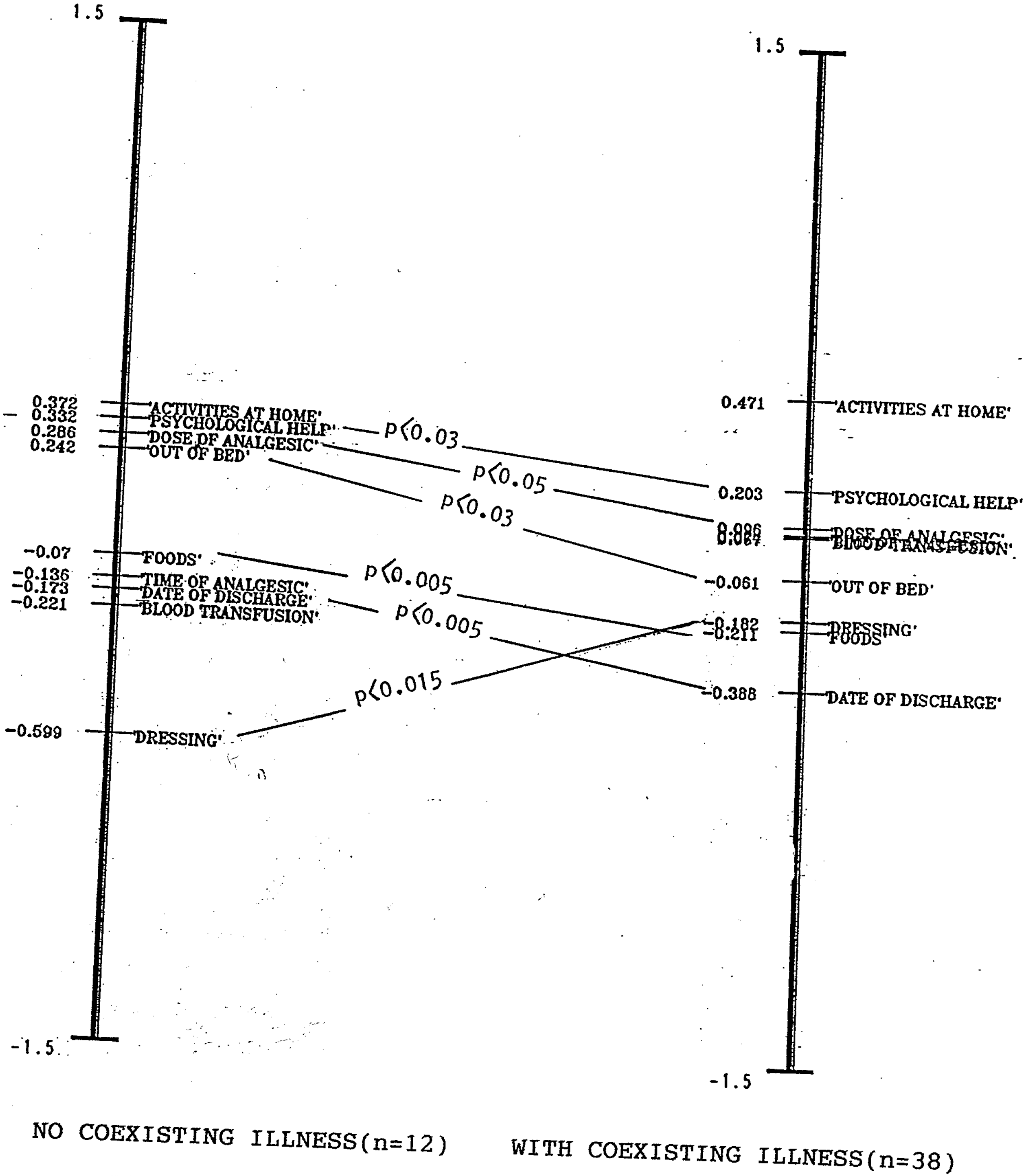


Figure 9. Comparison in ranking preferences for participation in nine postoperative care between patients with greater and less formal education using Thurstone's Law of Comparative Judgement.

Coexisting Illness

Whether or not patients had coexisting illnesses had significant effects on patients' responses. Patients with no coexisting illnesses (n=12) wanted more input in the following postoperative care decisions: when to first get out of bed after surgery ($p<0.03$), food ($p<0.005$), analgesic dosage ($p<0.05$), psychological assistance ($p<0.03$) and date of discharge ($p<0.005$) and less input into dressing changes ($p<0.015$) than patients who had coexisting illnesses (n=38). The first ranked postoperative care decision of patients both with and without coexisting illnesses was "What activities I should do and avoid doing when I go home." The span of the z scores in the group with coexisting illnesses was 0.859; in the group with no coexisting illnesses it was 0.971. Figure 10 illustrates the differences of opinions between patients with and without coexisting illnesses.



<u>Figure 10.</u> Comparison of patients with and without coexisting illnesses in ranking preferences for participation in nine postoperative care decisions using Thurstone's Law of Comparative Judgement.

Perceived Outcome of Surgery

Because there were only two patients who believed that surgery had not cured them, the results of the "not cured" group could not be analyzed validly. Patients who believed that surgery had been curative (n=22) wanted more input into decisions regarding dressing changes ($p<0.001$) and date of discharge ($p<0.03$) and less input into decisions regarding blood transfusions ($p<0.001$) than those who were not sure if surgery was curative (n=26). The first ranked postoperative care decision of patients both who believed they were cured and who were not sure of the surgical outcome, was "What activities I should do and avoid doing when I go home." The span of the z scores for the "cured" group was 0.691; for the "not sure" group the span was 0.948. Figure 11 depicts the differences between patients who believed they were cured and patients who were not sure if they were cured.

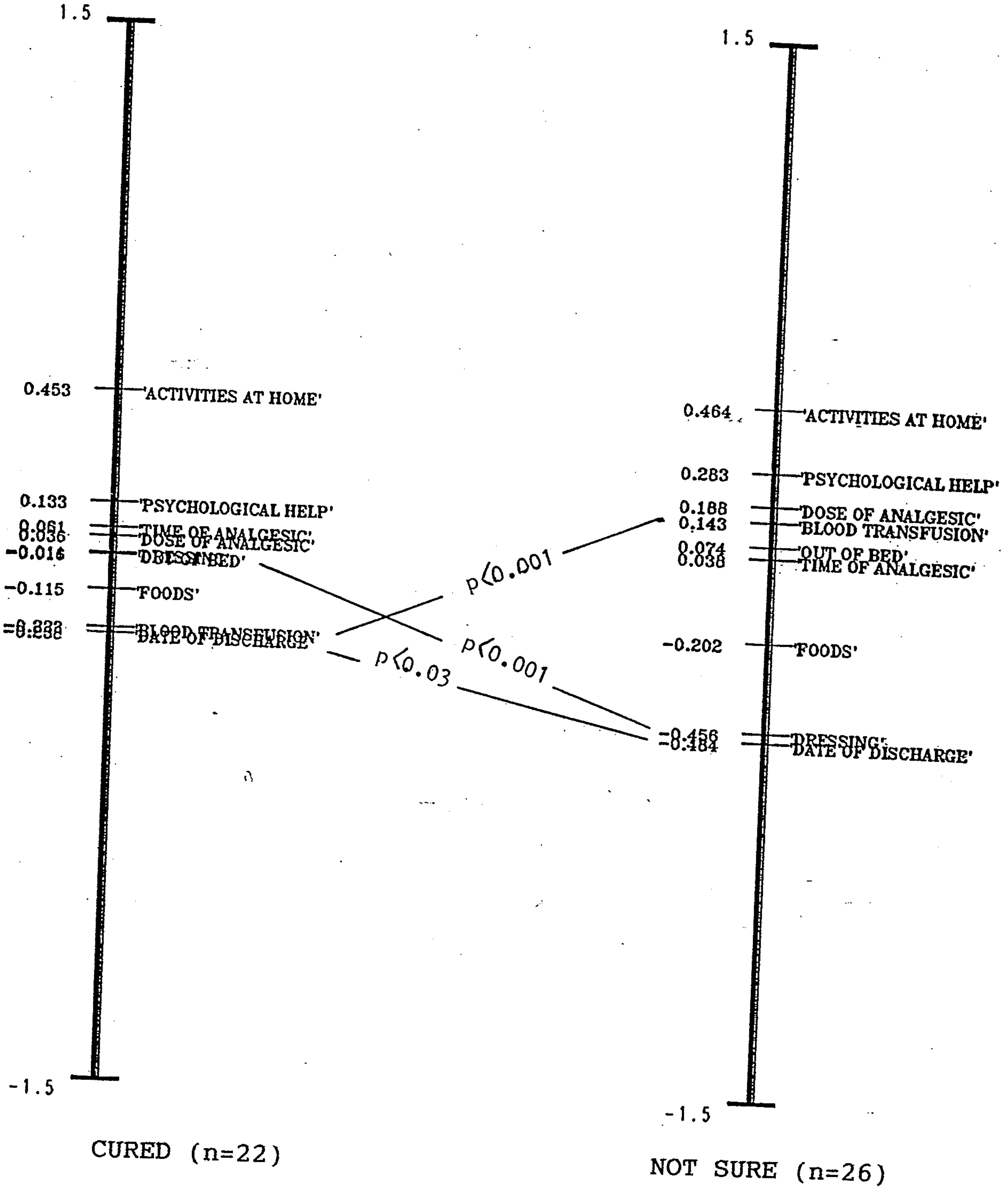


Figure 11. Comparison of patients who believed they were cured and those who were not sure of the surgical outcome when ranking nine postoperative care decisions using Thurstone's Law of Comparative Judgement.

Summary of Postoperative Care Decision Rankings

The most striking observation of the postoperative care decision rankings was that all categories of patients: male and female, young and old, those who resided in Winnipeg and those that did not, those with greater and lesser amounts of education, those with and those without coexisting illnesses, those who thought they were cured and those who were unsure, selected activities to do and avoid doing at home as the most important decision in which to participate.

Patient Concerns About the Tool

One patient (#7) indicated his disapproval of the paired comparisons questions stating, "I don't think much of this questionnaire. It's stupid. You are trying to prove something exists when it really doesn't. You can prove anything you want with statistics. I don't want to be part of this." After completing the paired comparison questionnaire, he declined further participation. The patient (#46) who left the majority of the paired comparisons unanswered stated that the paired comparisons left unanswered were equally unimportant to him. As indicated previously, this section of his data had to be deleted because it caused computation errors. Several patients voiced their displeasure in answering the paired comparisons. Some felt that they were repeatedly being asked the same questions. While they were completing the questionnaire, some subjects made statements which indicated that they believed postoperative care decisions should be made by the doctor mainly because they did not have sufficient knowledge to make these kinds of decisions. Patients also voiced statements about their trust in doctors to make decisions. Several stated that decision making about postoperative care was the appropriate role for the doctor and that it was inappropriate for patients to be doing this. After looking at the paired comparison questionnaire, one patient opted not to participate in the study because she wanted no part in treatment decision making.

Priority Postoperative Care Decisions

After the patients completed their responses to the paired comparisons they were asked to select one of the nine postoperative care decisions perceived as most important in which to participate. If a postoperative care decision other than the nine was preferred, space was provided for patients to write it in. No decisions were added. Although the frequency distribution of patients' first choice for participation in a postoperative care decision (see Table 8) was not the same as the rank ordering of decisions using Thurstone scales, there were similarities. The two most preferred postoperative care decisions most frequently selected were also the two most preferred decisions when the Thurstone rankings were used.

Table 8. Postoperative care decisions selected by patients as most important in which to participate (n=51).

Decision	Frequency	Percent	Z score
[a]PSYC	14	27.5	0.706
[b]ACTV	12	23.5	0.603
[c]BLOD	9	17.6	0.406
[d]DOSA	5	9.8	0.203
[e]TIMA	5	9.8	0.203
[f]OBED	2	3.9	0.100
[g]FOOD	2	3.9	0.100
[h]DISC	2	3.9	0.100
[i]DRSG	0	0	0.000

[a] If I should receive assistance in dealing with the psychological impact of my illness and surgery.

[b] What activities I should do and avoid doing when I go home.

[c] If I should have a blood transfusion.

[d] How strong a dose of pain medication I should receive.

[e] What time my pain medication should be given.

[f] When I should get out of bed for the first time after surgery.

[g] Which foods should be served to me.

[h] What day I should be discharged from the hospital.

[i] When my dressing should be changed.

Preference Roles for Decisional Control

As hypothesized, the majority of patients preferred passive decision making roles. Table 9 illustrates the frequency distribution produced by the five card unfoldings of patients' preferred roles in deciding to have surgical treatment.

Table 9. Distribution of surgical decision preference roles (n=50).

Preference Order	Roles				
	[a]A	[b]B	[c]C	[d]D	[e]E
First	1	8	12	16	13
Second	2	9	12	21	6
Third	2	14	25	7	2
Fourth	16	18	1	5	10
Fifth	29	1	0	1	19

[a] A: "I prefer to make the final selection about which treatment I will receive."

[b] B: "I prefer to make the final selection of my treatment after seriously considering my Doctor's opinion.'

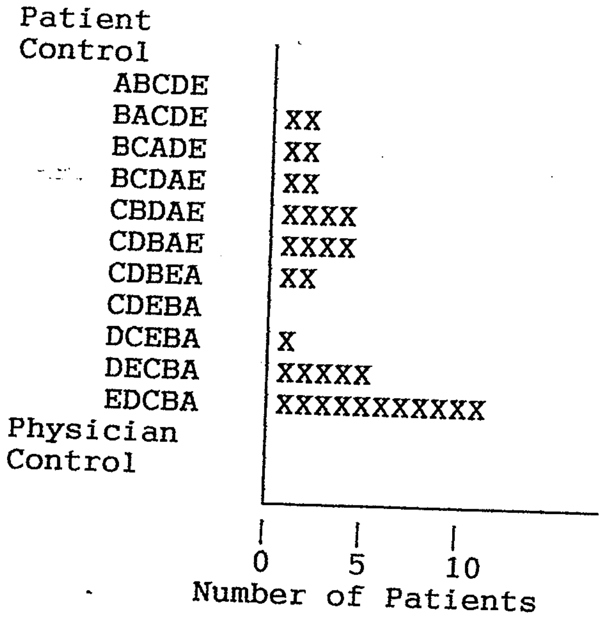
[c] C: "I prefer that my Doctor and I share responsibility for deciding which treatment is best for me."

[d] D: "I prefer that my Doctor makes the final decision about which treatment will be used, but seriously considers my opinion."

[e] E: "I prefer to leave all decisions regarding my treatment to my Doctor."

Control Preference Dimension

Unfolding Theory was used to determine which patients followed the theoretical dimension. It was hypothesized that the preference orders of the majority of patients would be consistent with the existence of a psychological dimension of keeping, sharing and giving away decision making control described by Degner and Russell (1988). It is possible to have 120 permutations of roles ABCDE. Only 11 of these permutations fall along the theoretical dimension. Figure 12 illustrates the distribution of decision making roles preferred by the 33(66%) subjects who followed the hypothesized theoretical dimension. Hypothesis 2 was not rejected. Of the 33 subjects, none fell into the extreme end of keeping control while one third occupied the extreme give away control position.



<u>Figure 12.</u> Surgical treatment decisional role preferences[a] which followed the hypothesized dimension of keeping, sharing, or ceding control (n=33)

[a] A: "I prefer to make the final selection about which treatment I will receive."
B: "I prefer to make the final selection of my treatment after seriously considering my Doctor's opinion.'
C: "I prefer that my Doctor and I share responsibility for deciding which treatment is best for me."
D: "I prefer that my Doctor makes the final decision about which treatment will be used, but seriously considers my opinion."
E: "I prefer to leave all decisions regarding my treatment to my Doctor."

Thurstone Scaling of Surgical Treatment Role Preferences

When Thurstone's Theory of Comparative Judgement was used to determine the rank order of patients' decisional role preferences. The proportion of times the roles listed across the rows of the matrix was favoured over the roles listed down the columns is illustrated in Table 10. The z scores of the proportions are provided in Table 11.

Table 10. Matrix of the proportions for surgical treatment decision preference roles (n=50).

	A[a]	B[b]	C[c]	D[d]	E[e]
A	0	0.3800	0.2800	0.3000	0.4000
B	0.6200	0	0.3000	0.3000	0.3800
C	0.7200	0.7000	0	0.3200	0.4000
D	0.7000	0.7000	0.6800	0	0.4200
E	0.6000	0.6200	0.6000	0.5800	0

[a] A: "I prefer to make the final selection about which treatment I will receive."

[b] B: "I prefer to make the final selection of my treatment after seriously considering my Doctor's opinion.'

[c] C: "I prefer that my Doctor and I share responsibility for deciding which treatment is best for me."

[d] D: "I prefer that my Doctor makes the final decision about which treatment will be used, but seriously considers my opinion."

[e] E: " I prefer to leave all decisions regarding my treatment to my Doctor."

Table 11. Matrix of normal deviates for surgical treatment decision preference roles[a] (n=50).

	A	B	C	D	E
A	0.00000	-0.30548	-0.58284	-0.52440	-0.25335
B	0.30548	0.00000	-0.52440	-0.52440	-0.30548
C	0.58284	0.52440	0.00000	-0.46770	-0.25335
D	0.52440	0.52440	0.46770	0.00000	-0.20189
E	0.25335	0.30548	0.25335	0.20189	0.00000
MEAN	0.33321	0.20976	-0.07724	-0.26292	-0.20281

[a] A: "I prefer to make the final selection about which treatment I will receive."

B: "I prefer to make the final selection of my treatment after seriously considering my Doctor's opinion.'

C: "I prefer that my Doctor and I share responsibility for deciding which treatment is best for me."

D: "I prefer that my Doctor makes the final decision about which treatment will be used, but seriously considers my opinion."

E: "I prefer to leave all decisions regarding my treatment to my Doctor."

The mean values in Table 11 indicate the preference orders of decision making roles. The means of the z scores of the preference roles listed in Table 11 corresponds to the preference order in Figure 13 however the axial rotation of the figure was turned so that the more favourably rated decision making roles are at the upper part of the scale and have higher scores. The z score span was 0.596. Figure 14 depicts the plot of the distribution of normal deviates which demonstrates the degree of variability of the z scores.

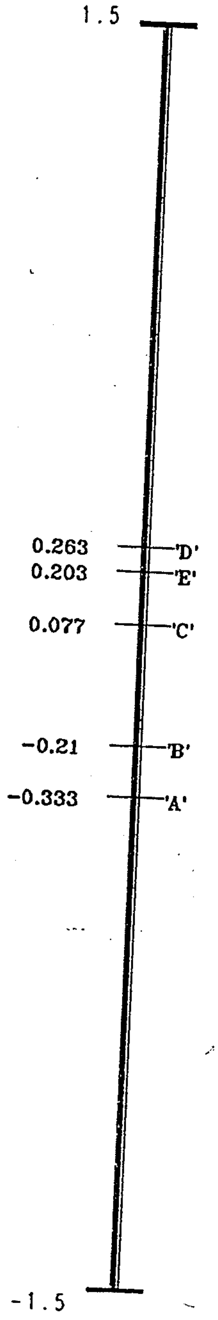


Figure 13. Thurstone scale of patients'(n=50) surgical treatment decision role preferences.

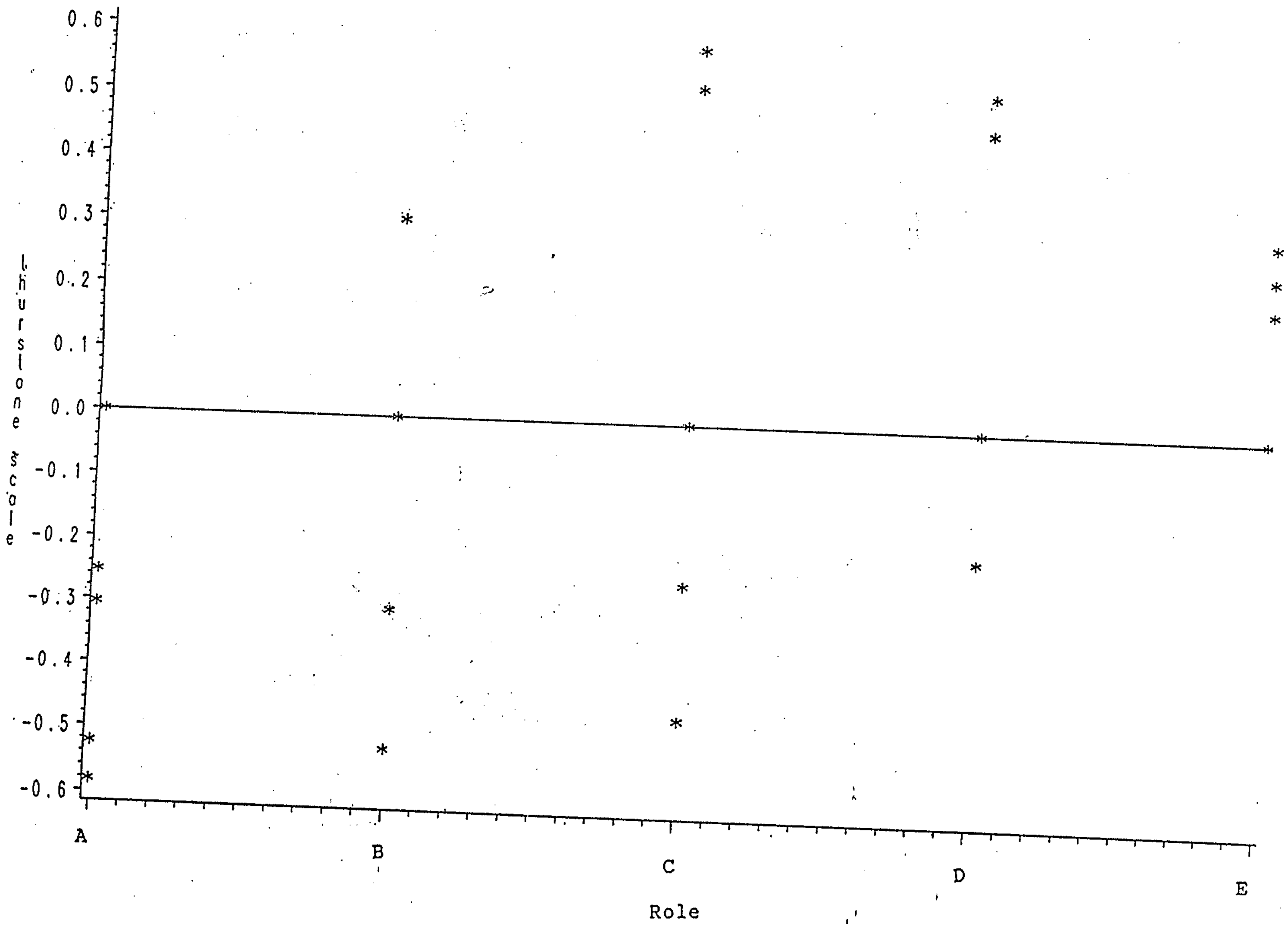


Figure 14. Z score ranges of patients' (n=50) surgical treatment decision role preferences.

The result of Kendall's coefficient of agreement indicates that the raters were in agreement to a significant degree. To establish significance the coefficient must be greater than 0. It was 0.08408. The associated Chi square test statistic was 53.55035. It had 10.63368 degrees of freedom and a p value of 0.0000001.

Factors Affecting Surgical Decision Making Role Preferences

Significant differences in preferred surgical treatment decision making roles in the various categories of subjects were found when the means of z scores of Thurstone scales of decision roles were subjected to pooled t tests. Appendix O contains tables of the z scores that were compared.

Gender

Role E was preferred by men but role D was preferred by women for deciding surgical treatment. The only significant difference between the z scores of men and women occurred at role E with men preferring it more than women ($p<0.001$). The span of the z scores in women was 0.638; in men the span was 0.561. Figure 15 illustrates the comparison of preference roles of men and women.

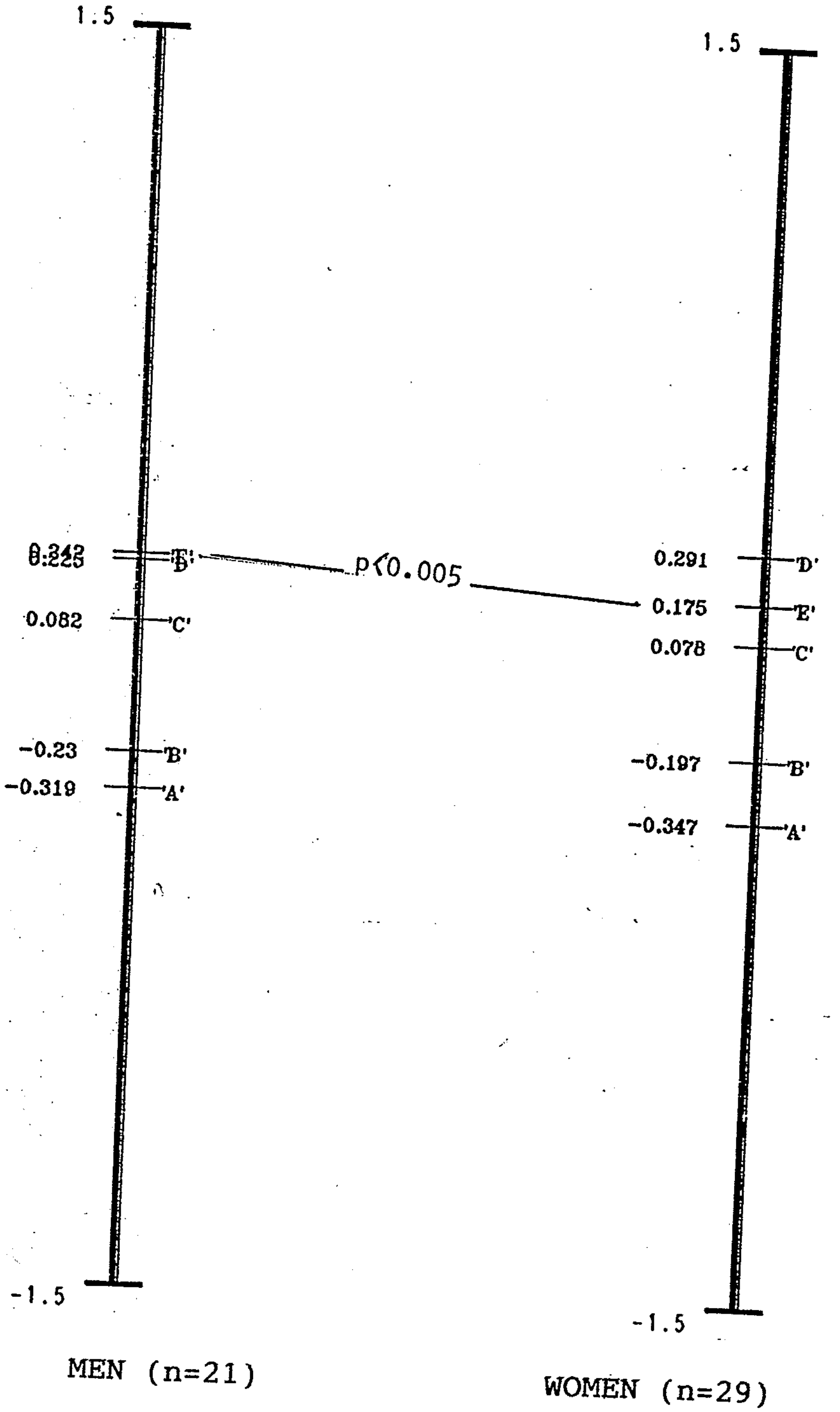
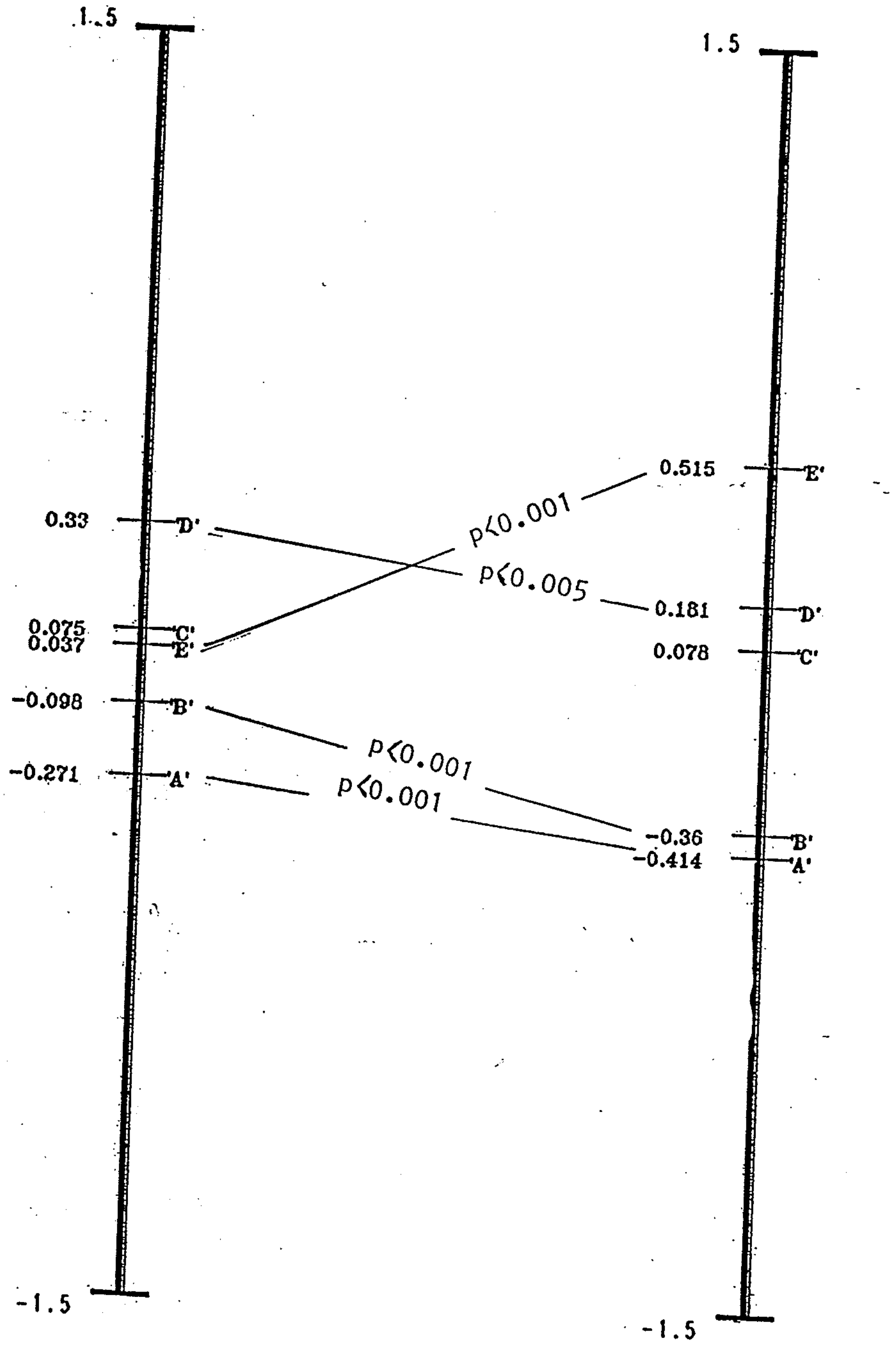


Figure 15. Comparison of men's and women's surgical treatment decision role preferences using Thurstone's Law of Comparative Judgement.

Age

When comparing scores of patients younger than 65 years with those who were 65 years or older, significant differences occurred in surgical treatment preference roles A, B, D and E. Younger patients preferred role D, their second choice was role C and their third choice was role E. Older patients preferred role E, their second choice was role D and their third choice was role C. Younger patients had a greater preference for role D ($p<0.005$) and older patients had a greater preference for role E ($p<0.001$). Older patients disliked roles A ($p<0.001$) and B ($p<0.001$) more than younger patients. The span of z scores in the older group was 0.929; in the younger group the span was 0.601. The comparison of decision role preferences in younger and older patients is illustrated in Figure 16.



LESS THAN 65 YEARS (n=27)   65 YEARS OR GREATER (n=23)

Figure 16. Comparison of younger and older patients' preferences for surgical treatment decision making roles using Thurstone's Law of Comparative Judgement.

Residence

Patients residing in Winnipeg had a greater preference for surgical treatment decision role E than those not residing in Winnipeg ($p<0.001$). Patients not residing in Winnipeg ranked role D first, C second and E third; Winnipeg residents ranked role E first, D second and C third. The span of z scores for the Winnipeg residents was 0.748 and for the non-Winnipeg residents it was 0.626. Comparison between decision role preferences of patients residing in Winnipeg and of patients not residing in Winnipeg is illustrated in Figure 17.

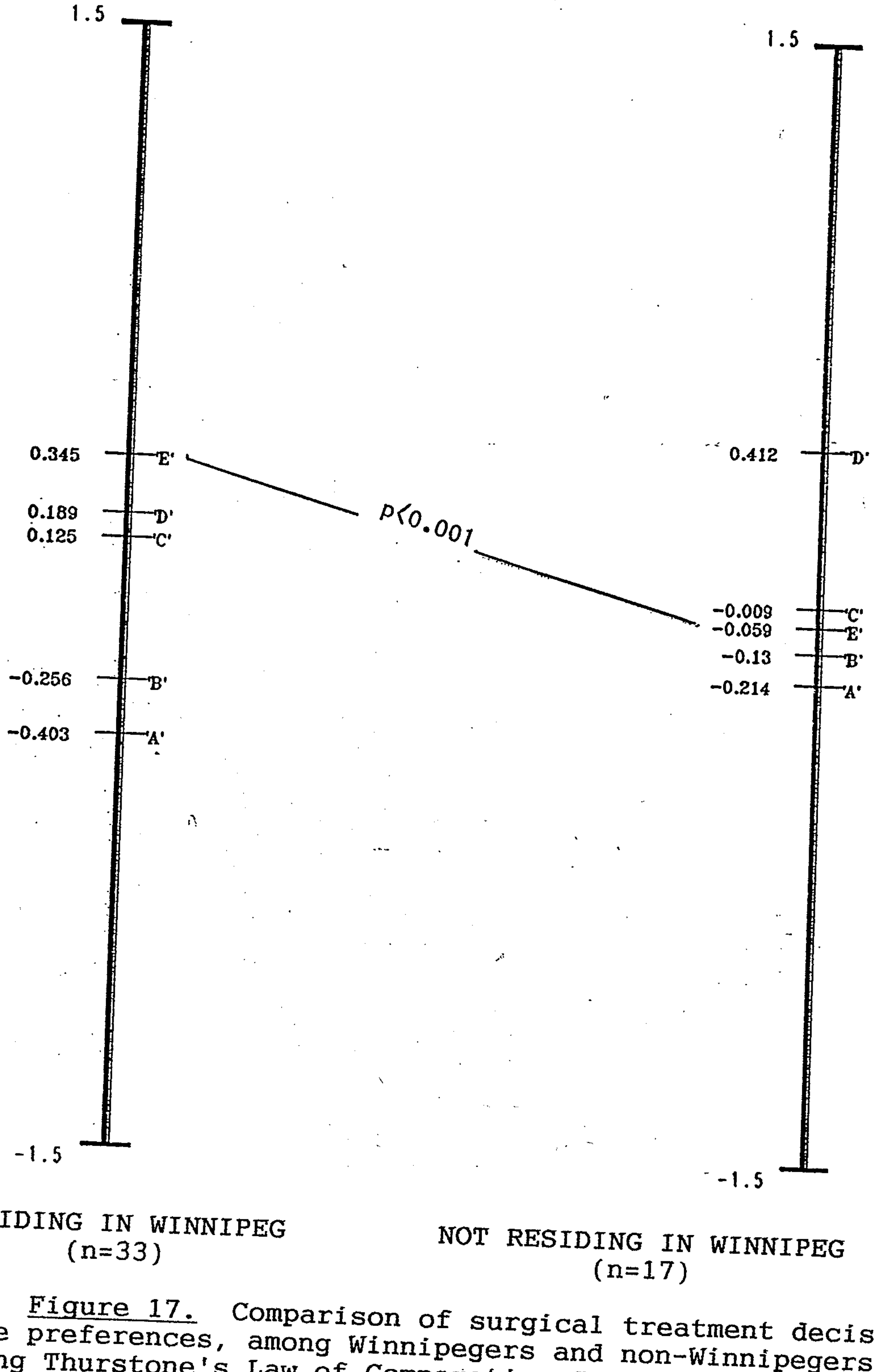
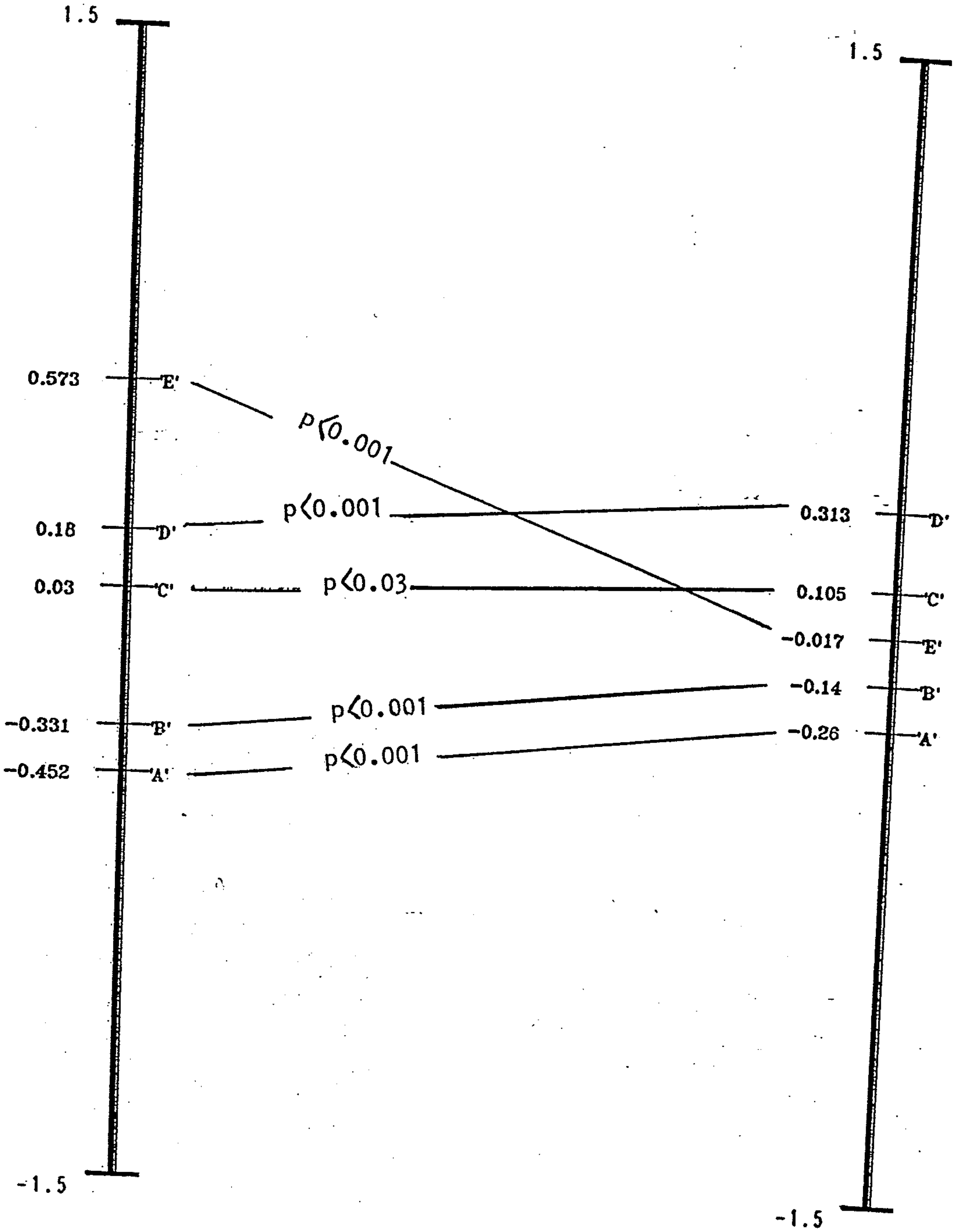


Figure 17. Comparison of surgical treatment decision role preferences, among Winnipegers and non-Winnipegers, using Thurstone's Law of Comparative Judgement.

Education

Level of education was associated with differences in surgical treatment role preferences. Patients who had less than high school graduation differed from those with high school graduation or greater education. Those with less education had a greater dislike of roles A ($p<0.001$) and B ($p<0.001$) and a greater preference for role E ($p<0.001$). Patients with more education had a greater preference for roles C ($p\leq0.03$) and role D ($p<0.001$). Those with more education ranked role D first, C second and E third; those with less education ranked role E first, D second and C third. The span of the z scores was 1.025 in patients with less education and 0.573 for those with more education. Figure 18 illustrates the differences in decision role preferences associated with lesser and greater amounts of formal education.



LESS THAN HIGH SCHOOL GRADUATION (n=20)

HIGH SCHOOL GRADUATION OR GREATER (n=30)

Figure 18. Comparison of surgical treatment decision role preferences, among patients with greater and lesser amounts of education using Thurstone's Law of Comparative Judgement.

Coexisting Illnesses

Patients with coexisting illnesses differed from those with no coexisting illnesses in that those with coexisting illnesses had a greater distaste for roles A ($p<0.05$) and B ($p<0.01$) and a greater preference for role E ($p<0.001$) when selecting surgical treatment decision roles. Patients with coexisting illnesses ranked role E first, D second, C third and B forth. Patients with no coexisting illnesses ranked the role D first, B and C tied for second, and then E. The span of scores was 0.698 in patients with coexisting illnesses; 0.517 in patients without coexisting illnesses. Figure 19 illustrates the differences in decision role preferences associated with coexisting illnesses.

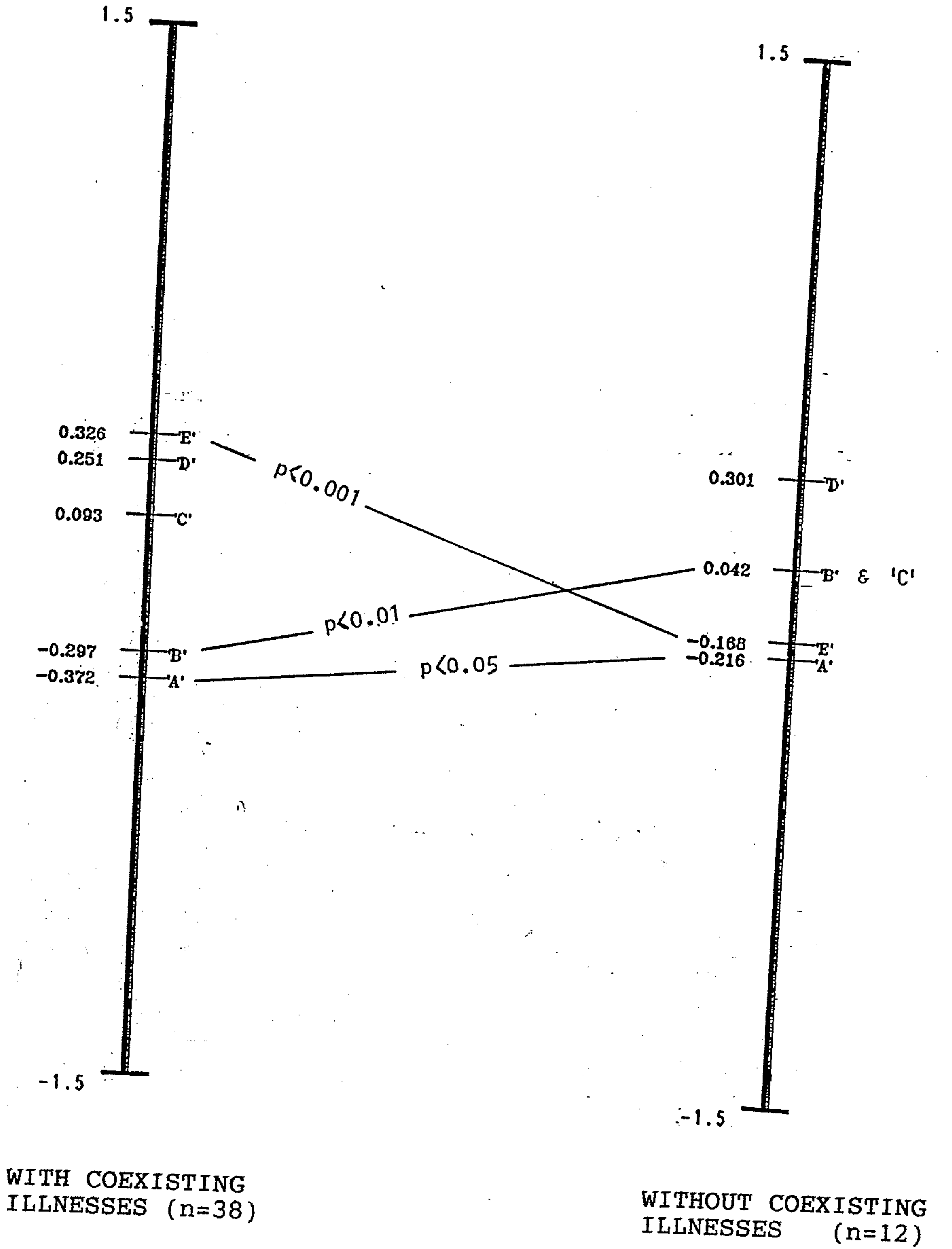


Figure 19. Comparison of surgical treatment decision role preferences, among patients with and without coexisting illnesses, using Thurstone's Law of Comparative Judgement.

Perceived Outcome of Surgery

When selecting surgical treatment preference roles, patients who believed surgery had cured them indicated a greater dislike for role A ($p<0.001$) and a greater preference for role E ($p<0.001$) than those who were unsure of the surgical outcome. Those who were unsure had a greater preference for role D ($p<0.01$). Patients who believed they had been cured ranked role E first, D second, C third, B forth and A last. Patients who were unsure ranked role D first, E second, C third, A fourth and B last. The span of z scores was 0.897 in patients who believed they were cured; 0.655 in unsure patients. Figure 20 illustrates patients' decisional role preferences associated with their beliefs about the outcome of surgery.

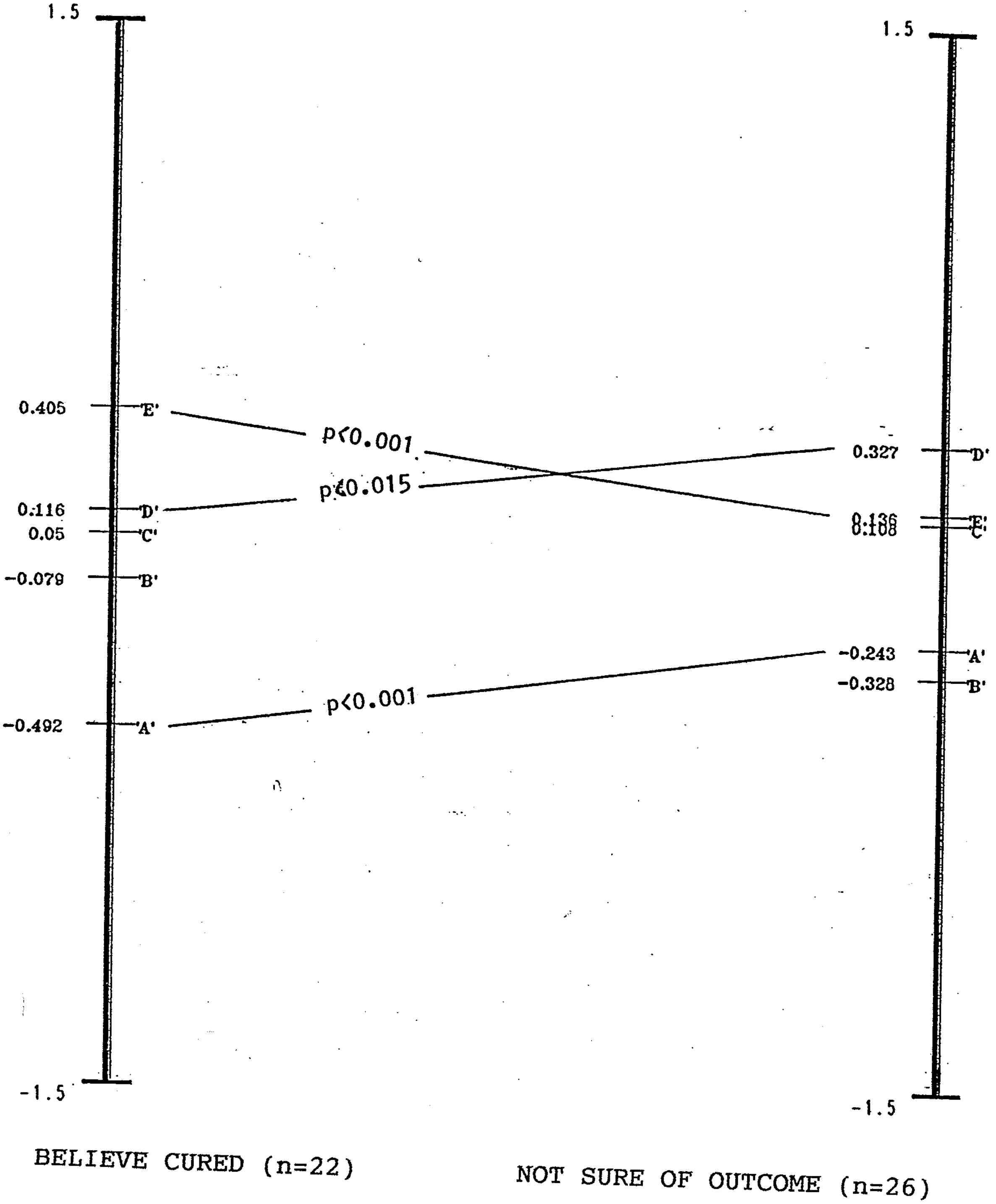


Figure 20. Comparison of surgical treatment decision role preferences among patients who believed they were cured and those who were unsure of the surgical outcome, using Thurstone's Law of Comparative Judgement.

Summary of Surgical Treatment Decision Role Preferences

Role D was the first choice of patients who were female, younger, had no coexisting illnesses, unsure if surgery had cured them, had high school graduation or greater education, and did not reside in Winnipeg. Role E was the first choice of patients who were male, older, had coexisting illnesses, believed they were cured by surgery, had not graduated from high school, and resided in Winnipeg. Role A was ranked last by all categories of patients except those who were unsure if surgery had cured them. Unsure patients ranked role B last and role A second last. In patients with no co-existing illnesses roles B and C tied for second highest place and role E was ranked second last. Role B was ranked second last by all except two categories of patients: unsure patients and patients with no coexisting illnesses.

Decision Role Categories

From the five roles a patient might select in the decision making process, three role categories were created. The active category was composed of decisional roles A and B. The collaborative category was equated to decisional role C. Decisional roles D and E comprised the passive category.

Preferred Postoperative Care Decision Making Role Categories

Using each patient's postoperative care decision selected as most important in which to participate, the preferred postoperative care decision making role was elicited for that decision. One subject did not complete the role selection for postoperative care decisions because she was having pain. Comparison of roles involving postoperative care decisions were therefore based on 49 subjects. The resulting frequency distribution is displayed in Table 12. Decided passivity was revealed by the 14 patients who indicated that they preferred to take a passive role in the postoperative care decision in which participation was most important to them.

Table 12. Distribution of preference role category by the most important postoperative care decision.

Post-Operative Decision	Preference Role Category			
	Active	Collaborative	Passive	Total
[a]OBED	1(2.04%)	0(0.00%)	1(2.04%)	2(4.08%)
[b]FOOD	0(0.00%)	1(2.04%)	1(2.04%)	2(4.08%)
[c]DRSG	0(0.00%)	0(0.00%)	0(0.00%)	0(0.00%)
[d]DOSA	2(4.08%)	3(6.12%)	0(0.00%)	5(10.20%)
[e]TIMA	3(6.12%)	2(4.08%)	0(0.00%)	5(10.20%)
[f]BLOD	2(4.08%)	4(8.16%)	3(6.12%)	9(18.37%)
[g]PSYC	2(4.08%)	8(16.33%)	2(4.08%)	12(24.49%)
[h]ACTV	2(4.08%)	5(10.20%)	5(10.20%)	12(24.49%)
[i]DISC	0(0.00%)	0(0.00%)	2(4.08%)	2(4.08%)
Total	12(24.49%)	23(46.94%)	14(28.57%)	49(100%)

[a] When I should get out of bed for the first time after surgery.

[b] Which foods should be served to me.

[c] When my dressing should be changed.

[d] How strong a dose of pain medication I should receive.

[e] What time my pain medication should be given.

[f] If I should have a blood transfusion.

[g] If I should receive assistance in dealing with the psychological impact of my illness and surgery.

[h] What activities I should do and avoid doing when I go home.

[i] What day I should be discharged from the hospital.

Comparison of Preferred Surgical and Preferred Postoperative Decision Roles

Preferred postoperative care decision role categories were compared with the preferred surgical treatment decision role categories. Twenty (40.82%) subjects preferred the same role category in both situations. The majority of patients preferred to take a passive decision role with regard to the surgical treatment. Slightly less than half (46.94%) the sample preferred to have a collaborative role in postoperative decisions. Chi square testing indicated that there were no significant differences (DF=4, Chi square value=3.519, p=0.475) between preferred surgical and postoperative care decisional role categories. However, chi square may not be a valid test because 56% of the cells had expected counts of less than 5. Therefore no measure of significance can be stated.

When preferred postoperative care active and collaborative categories were collapsed to increase cell size (see Table 13) there were no significant differences (DF=1, Chi square value 1.217, p=0.270). Therefore Hypothesis 3, "Patients' preferred role in deciding to have surgery will be the same as their preferred role in making the postoperative care decision in which they selected as most important to participate," has not been rejected.

Two justifications for collapsing active and collaborative preferred roles are given. (1.) Only one subject indicated a preference for role A in deciding to have surgery. This subject's second preference role was D which indicated that he made a serious mistake in the process of rank ordering his preferences. While doing the card sort, this subject kept repeating, "The doctor knows best. It's best to do whatever the doctor says." Although he has been classified as active, this mistake and his verbalizations tend to invalidate his preference for role A. (2.) The mistakes made by 17(34%) subjects who did not follow the hypothesized theoretical dimension were analyzed. The first instance of a mistake was counted. Mistakes in placement of role B occurred ten times whereas role D was involved in mistakes three times, role E two times, and roles A and C only once each. It would appear that role B was the most difficult role for subjects to distinguish from other roles close to it. Several subjects verbalized difficulty in differentiating roles B and C. If B and C are very close together in meaning, so close that most of the errors centred on role B, then it is logical to collapse B and C into one category.

Table 13. Comparison of preferred surgical treatment and preferred postoperative care decision making role categories.

Preferred Surgical Treatment Role	Preferred Postoperative Care Role		Total
	Active/Collaborative	Passive	
Active/ Collaborative	16(32.65%)	4(8.16%)	20(40.81%)
Passive	19(38.78%)	10(20.41%)	29(59.19%)
Total	35(71.43%)	14(28.57%)	49(100%)

Chi square value=1.217, DF=1, p=0.270

Comparison of Assumed Surgical and Assumed Postoperative Decision Roles

Comparing role categories that patients perceived they assumed for deciding surgical treatment and for postoperative care was complicated by 20(40.82%) subjects who indicated that the postoperative care decision being analyzed had not yet been made at the time of data collection. Reports of no decision having been made yet was reported by ten subjects whose most important postoperative decision for participation in decision making was related to activities to do and avoid at home (20.41% of total, 83.33% of home activities); seven related to psychological help (14.29% of total, 58.33% of psychological help); two for date of discharge date (4.08% of total, 100% of discharge date) and one for blood transfusions (2.04% of total, 11.11% of blood transfusions).

Although no significant differences were demonstrated between assumed surgical treatment and assumed postoperative care decision making role categories, warnings were given by the SAS program that Chi square may not be a valid test because cells had expected counts of less than 5. Warnings occurred when the "no decision" group of patients were both included in and excluded from analysis. Therefore no statement can be made about the congruence or lack of same between these groups. Table 14 illustrates the distribution of assumed decision role categories patients perceived they assumed for surgical treatment and postoperative care decisions.

Table 14. Comparison of assumed surgical treatment role categories and assumed postoperative decision care role categories

Assumed Surgical Treatment Decision Role Category	Assumed Postoperative Care Decision Role Category			Total
	Active/ Collaborative	Passive	No Decision	
Active/ Collaborative	4 (8.16%)	5 (10.20%)	4 (8.16%)	13 (26.53%)
Passive	9 (18.37%)	11 (22.45%)	16 (32.65%)	36 (73.47%)
Total	13 (26.53%)	16 (32.65%)	20 (40.82%)	49 (100.00%)

Comparison of Preferred and Assumed Decision Role Categories

Surgical treatment and postoperative care decision making role categories were considered when addressing Hypothesis 4: "Patients preferring collaborative and active decision making roles will be greater in number than those who assume collaborative and active roles."

Preferred and Assumed Surgical Treatment Decision Role Categories

For surgical treatment, 21(42%) subjects preferred to take active and collaborative decision roles and 29(58%) subjects preferred passive decision roles. However 14(28%) subjects perceived that they had assumed active or collaborative decision roles and 36(72%) perceived that they had assumed passive decision roles. Using Chi square, the difference between preferred and assumed surgical treatment decision roles were significant (DF=1, value=10.676, p=0.001). The distribution is displayed in Table 15.

Table 15. Comparison of preferred and assumed surgical treatment decision role categories.

Preferred Surgical Treatment Decision Role	Assumed Surgical Treatment Decision Role		
	Active/ Collaborative	Passive	Total
Active/ Collaborative	11(22%)	10(20%)	21(42%)
Passive	3(6%)	26(52%)	29(58%)
Total	14(28%)	36(72%)	50(100%)

Chi square value=10.676, DF=1, p=0.001

Preferred and Assumed Postoperative Care Decision Role Categories

For deciding postoperative care decisions, 71.4% preferred to take active or collaborative role categories and 28.6% preferred to take passive role categories (n=49). When collecting data to determine the actual role, 20(40.8%) subjects stated that the decisions being examined had not yet been made. Of the 29 subjects whose most important postoperative care decision had been made, 13(44.83%) indicated that they took active or collaborative roles and 16(55.17%) took passive roles. Chi square testing indicated that there was a significant difference (DF=1, Value=6.147, prob=0.013 when the no decision group was excluded; DF=2, Value=7.105, prob=0.029 when the no decision group was included) between preferred and active postoperative care decision roles. However, the warning that Chi square may not be a valid test was given by the SAS program because 50% and 33% of the respective cells had expected counts of less than 5. Lack of sufficient sample size precludes drawing conclusions about the difference between assumed and preferred roles for postoperative care decisions. Comparison of preferred and assumed role categories for postoperative care decisions is displayed in Table 16.

Table 16. Comparison of preferred and assumed role categories for postoperative care decisions.

Preferred Postoperative Care Role	Assumed Postoperative Care Role			
	Active/ Collaborative	Passive	No Decision	Total
Active/ Collaborative	13 (26.53%)	10 (20.41%)	12 (24.49%)	35 (71.43%)
Passive	0 (0%)	6 (12.24%)	8 (16.33%)	14 (28.57%)
Total	13 (26.53%)	16 (32.65%)	20 (40.82%)	49 (100.00%)

Divergence between patients' preferred and actual decision making role categories was greatest when active and collaborative role categories were preferred. When deciding surgical treatment, 72% patients perceived that they had assumed their preferred role, 22% assumed a more passive role and 6% assumed a more active role than preferred. When the "no decision" group was deleted from calculations about postoperative care decisions, 65% assumed their preferred role, 35% assumed a more passive role and none assumed a more active role than preferred. Patients who preferred passive roles assumed them 89.66% of the time for surgery decisions and 100% of the time for postoperative care decisions. However, patients preferring active and collaborative roles assumed their preferred roles 47.62% of the time for deciding surgical treatment and 56.52% of the time for deciding postoperative care.

Decision Making Role Categories and Postoperative Care Decisions

Pooled t tests were used to determine if there were differences in the ranking of postoperative care decisions in patients categorized by the preferred and assumed decision making roles. Tables of the z scores are in Appendix P.

Preferred Surgical Treatment Decision Making Role Categories

Patients who preferred active-collaborative decision making role categories for surgical treatment (n=21) ranked involvement in postoperative decisions about analgesic dosage ($p<0.05$) and blood transfusions ($p<0.001$) higher, and ranked dressing change ($p<0.005$) lower than those who preferred a passive role (n=29). The most preferred postoperative care decision was activities to do and avoid at home in both preferred passive and preferred active-collaborative surgical decision role categories. The span of z scores in patients who preferred passive roles was 0.857. The span was 0.940 in patients preferring active-collaborative roles.

Preferred Postoperative Care Decision Making Role Categories

Patients who preferred an active-collaborative decision making role categories concerning postoperative decisions ranked involvement in postoperative decisions about when to first get out of bed after surgery ($p<0.03$), blood transfusions ($p<0.001$) and psychological assistance ($p<0.001$) higher than patients who preferred a passive role (n=14). The most preferred postoperative care decision was activities to do and avoid at home in both preferred passive and preferred active-collaborative postoperative care decision role categories. The span of z scores in patients preferring passive roles was 0.905. In patients preferring active/collaborative roles the span was 0.773.

Assumed Surgical Treatment Decision Making Role Categories

Patients who assumed an active-collaborative decision making role categories concerning surgical treatment (n=14) ranked involvement in postoperative care decisions about analgesic dosage ($p<0.03$), blood transfusions ($p<0.001$) higher than patients who assumed a passive role (n=36). The most preferred postoperative care decision was activities to do and avoid at home in both assumed passive and assumed active-collaborative surgical decision role categories. The span of z scores in patients assuming passive roles was 0.866. In patients assuming active-collaborative roles the span was 0.759.

Assumed Postoperative Care Decision Making Role Categories

Patients who assumed active-collaborative role categories in postoperative care decisions (n=14) ranked involvement in postoperative care decisions concerning when to first get out of bed after surgery ($p<0.001$) and food ($p<0.001$) higher than those who assumed a passive role. The most preferred postoperative care decision was activities to do and avoid at home in both assumed passive and assumed active-collaborative postoperative care decision role categories. The span of z scores in patients assuming passive roles was 0.748. In patients assuming active/collaborative roles the span was 0.936.

Patients' Explanations for Assumed Decision Making Roles

Patients (n=13) who had actual decision roles that were two or more scale differences apart, were asked if they had attempted to achieve their preferred decision making role. Only one patient with breast cancer made an attempt.

> "I had to pull information out of my doctor. She would not give me the reasons why I needed the operation. She simply said it was too technical. When my path report came back she did not let me know right away. Because of this and other problems I switched doctors. Eight weeks had passed from the time she told me I needed surgery to the time she told me that she would not be doing the surgery herself but that I would need to consult with another doctor. More time was wasted in setting up an appointment with the consulting doctor. I had enough, so I went to see a different doctor. I have not had any difficulty obtaining information from the second doctor. She (original doctor) was very taken aback when I told her why I switched doctors."

Patients who did not attempt to take action to achieve their preferred surgical treatment decision making role offered the following comments when asked what prevented them from taking action.

> "I became very depressed".
>
> "Things change when you are suddenly in this situation. I needed help. I needed to have faith in my doctor. I had to rely on the expertise of the doctors."
>
> "The nurses don't have time to discuss things with me. As soon as one sits down to have a social conversation she is called away. She says she will be back in two minutes but she usually doesn't come back for a couple of hours. No nurse has brought up the subject of cancer. I think they should have. I'm having a hard time coping. I'm not going to bring it up now because I don't want anything to interfere with me going home tomorrow."
>
> "My relationship with the specialist has not been good. It started badly. He did not come to see me. Instead I was only seen by the residents and interns. I had to demand that he come to talk with me personally. He didn't explain what could happen. I was not given an explanation that I could understand. It was not in layman's language. Once the biopsy was done there was no turning back. I was told it was going to be a small operation. I wasn't told about the radiotherapy. I was told everything would be ok - now its not ok. I wasn't told that I would have to wait to find out results from reports from the operation. I need to know what's going to happen. They should have told me that they were not sure yet rather than telling me everything was ok. I didn't know what to ask. They should have told me."
>
> "I had to wait six weeks to have my mammogram. During that time my lump grew three time the size. I had to wait so long that my role in decision making was taken away from me."
>
> "There was no other choice in my case. I had to have surgery."
>
> "Time. The decision had to be made in a hurry. The doctor has 27 years of experience. I have none.
>
> "I was too scared."

Patients who did not attempt to take action to achieve their preferred postoperative care decision making role offered the following comments when asked what prevented them from taking action.

Blood transfusions:

> "The doctor must have decided that I didn't need a blood transfusion. There was no need to discuss it with me."

> "I was not in a position where I could make decisions. I had to trust that the doctor would make the right decision."

Dose of analgesic:

> "I wasn't asked. My pain was controlled ok so there was no need to say anything."

Out of Bed:

> "I was heavily drugged. I would have preferred more information about why it was important and how to do it so it wouldn't hurt so much"

Four of the patients whose actual role was two or more scale differences from their preferred role indicated that the nurse did not play a role in helping or hindering preferred role achievement. Four patients stated that nurses played helping roles and four patients stated that nurses played hindering roles. Providing information was identified by three patients as the helping role that nurses played. One patient cited listening as the helpful nursing role. Patients who indicated that nurses played hindering roles made the following comments.

"I haven't had the same nurse for more than one day in

> a row. As a result, the nurses don't know me and they don't seem to be involved. Only one nurse had introduced herself and indicated that she cared."

> "The nurses did not bring up the subject of cancer. They only seemed to be interested in my physical condition. They don't seem to have the time to talk"

> "She should have given me more information about getting up."

Patients (n=45) who had actual decision roles that were one or less scale differences apart were asked if they could identify the reason why they had succeeded in so closely achieving their preferred decision making roles. Up to three reasons were given by several patients. The following categories were created from the responses given: Provision of information/advice/guidance (n=17), doctor's knowledge/expertise (n=15), prefer to follow guidance/expectations of health professional (n=11), patient lacks sufficient knowledge (n=10), used other resources such as library, self and/or family (n=9), doctor provided options (n=6), patient concerns taken into consideration (n=6), no choice/have surgery or die (n=3).

Nursing actions patients identified as helpful in achieving preferred decision making roles were classified into the following categories: provision of information/options (n=8), made decisions/took action/advised (n=4), listened/provided psychological support (n=4), complied with patient's wishes (n=3), encouraged to have confidence in doctor (n=1), encouraged to live for self (n=1). Nurses not being involved in the decision making process was identified by 21 patients.

Only one patient indicated the need for more information but did not let the nurse or doctor know about it. Not knowing what to ask was the reason given for not letting the nurse or doctor know that information was needed.

Patients' Learning Needs

The 50 item Patient Learning Needs Scale was used to determine the amount of information patients believed was important for them to know before they went home. The learning needs scale consisted of seven categories of information. The number of items related to each category was not equal. Therefore the scores were converted from raw numbers to percentages so that the different categories of the scale could be more easily compared. The univariate statistics for each category, displayed in Table 17, demonstrate a ceiling effect for most categories.

Table 17. Percentages of learning needs: Univariate statistics.

Learning Need	Median	3rd Quartile	Mean	Standard Deviation	n
[a] MED	87.14	94.28	75.42	26.88	48
[b] ADL	73.33	84.44	72.4	15.91	50
[c] COMFU	55.71	74.29	56.17	23.97	50
[d] FEEL	62.	80.	60.4	24.37	50
[e] TXCOMP	86.67	95.56	83.17	13.91	49
[f] QLIFE	80.	92.5	78.80	15.78	48
[g] SKIN	52.	76.	56.88	22.80	50
TOTAL	68.94	78.82	67.92	15.05	50

[a] Medications;
[b] Activities living;
[c] Community/follow-up;
[d] Feelings condition;
[e] Complications/treatment;
[f] Quality of life;
[g] Skin care.

Learning Needs and Decision Making Roles

The relationship of preferred and actual decisional roles to perceived learning needs was analyzed and. Only patients who assumed active and collaborative decision making roles when deciding about surgery indicated a greater need for information than those patients who assumed passive roles. The analysis of variance of patients who assumed active/collaborative and passive roles for surgical treatment decisions is displayed in Table 18.

Table 18. Analysis of variance of information needs of patients who assumed active/collaborative decision making roles and who assumed passive decision making roles.

Assumed Surgical Decision Making Role	n	Mean PLNS[a] score	Standard Deviation
Active/ Collaborative	13	77.28%	13.92
Passive	36	65.14%	14.03

F Value = 4.700, prob > F = 0.0351, Kruskal-Wallis Test Chi square = 5.4454, DF=1, Prob > Chi square = 0.0196.

[a] Patient Learning Needs Scale

When the learning needs of patients who assumed collaborative roles for surgery decisions (n=9, mean=76.74) were compared to patients who assumed active and passive roles for surgery decisions (n=41, mean=65.98), those who assumed collaborative roles had more learning needs (F Value=4.003, Prob > F 0.0511, Kruskal-Wallis Chi Square = 5.1078, DF=1, Prob > Chi square = 0.0238). Hypothesis 5 "Patients who assume collaborative and active decision making roles will indicate the same information needs for self care management at home as patients who assume a passive decision making role" has been rejected. There were no significant differences in learning needs between patients in other role categories. Nonparametric procedures patients in other role categories. Nonparametric procedures for analysis of variance were used because the distribution of learning needs scores being analyzed did not form a normal curve.

Summary

A convenience sample of postoperative cancer patients was described according to gender, age, education, residence, type of cancer, type of surgery, days since informed of diagnosis, number of coexisting illnesses, and beliefs about the outcome of surgery. Preferred and actual roles for participating in decision making were compared using Chi square. Most patients preferred passive roles. Patients who preferred passive roles usually achieved them. Only half the patients who preferred collaborative or active roles assumed their preferred roles. Patients' preferred roles for participation in decisions related to the surgical treatment and postoperative care were not significantly different and were analyzed using Thurstone's Law of Comparative Judgement. Asking patients to pick the postoperative care decision that was most important for them to participate in produced similar results to the paired comparison ranking procedure. All categories of patients ranked activities to do and avoid doing at home as the most important postoperative care decision for participation.

Factors that affect the ranking of postoperative care decisions and decision role preferences were identified. Patients provided explanations for their actual decision making roles. Patients who assumed an active/collaborative decision making role indicated that they had more pre-discharge information needs.

CHAPTER 5

DISCUSSION

This study has increased nursing knowledge about postoperative cancer patients' roles in treatment decision making. It explored factors that may affect patients' preferred and assumed roles in decision making and examined patients' hierarchial preference rankings of participation in making postoperative care decisions. This chapter will discuss the relationship of scale ranking and clustering of postoperative care decisions, preferred and assumed decision making roles, information needs and patients' perceptions of their situations. Determining patients' preferences is an important first step in determining if patients are achieving their preferences. Patients' achievements in assuming their preferred roles in treatment decision making are important measurements of the quality of health outcomes (Taylor, 1993). Determining the factors related to decision role preferences and roles achieved have implications for health care providers, educators and researchers involved with postoperative cancer patients.

Methodological Issues

Unfortunately several methodological problems became evident as the study progressed. The first problem was associated with the instrument that was created by this researcher to determine the ranking of patients' preferences for participation in postoperative care decisions. It became evident that the data collection method was not user friendly. Patients expressed the feeling that they were being asked the same questions repeatedly. The questions were not relevant to extremely passive patients. The span of the z scores on almost all the Thurstone Scales was narrow. This meant that the opinions the patients were expressing were weak. There were high numbers of circular triads and 16% of subjects were not sure of many of their answers. Extremely passive patients were required to decide on a preference between two choices, both of which were distasteful to them, perhaps indiscriminately distasteful. Therefore they probably were not committed to the decision they selected. Therefore the validity of the results is questionable. The lesson to be learned: Ensure the data collection tool is appropriate for the subjects.

A second problem that arose during data collection was a lack of explicitness in the instructions for evaluating the postoperative decisions and for measuring information needs. The problem with the instructions on the postoperative decisions questionnaire is discussed in a later section. The instructions to the patient in the tool for measuring information needs, indicated the subject should make his or her "choice based on how important you think it is to learn about an area before you go home" (Bubela & Galloway, 1990). This could have meant, how much more information do you think you need about an area before you go home? Or, it could have meant, how much information do you think is necessary for you to have about each area before you go home? This researcher did not realize the ambiguity of the question until after a subject requested an explanation. The second interpretation was used and verbally given to all further subjects. Lesson to be learned: Even if the tool has been rated as valid and reliable, the researcher should pretest all tools on several people before using them in a study.

A third problem arose after patients selected priority decisional preferences of postoperative care decisions. It was discovered that the decision selected by 40% of the patients had not yet taken place. This meant that comparisons of preferred and assumed postoperative care decisions, as well as comparisons of assumed postoperative care decisions and assumed surgical decisions could not be carried out in a valid manner. Although the postoperative decisions of home activities and the date of discharge were relevant to patients, the time frame for collecting data for these decisions was inappropriate for this sample. It would appear that, in this setting, decisions related to activities to do at home, psychological help, and date of discharge, are often not discussed and decided with patients who are within three days of discharge. Lesson to be learned: Be familiar with the setting in which the data are to be collected. It would seem that many of these patients were interested in taking part in the decision making process about home activities and psychological help. Perhaps three days within discharge is an appropriate time for nurses to be discussing these topics with postoperative cancer patients. Although date of discharge was not a high priority decision for patient involvement, many of them were asking the researcher if she knew when they would be discharged. Discharge date seems to be an information need but not a decisional need.

Problems associated with Thurstone Scales will be discussed under that heading. It is important to plan every detail of a research study to prevent methodological problems such as these from happening.

Thurstone Scales

Thurstone scales were used to determine the rank ordering of both postoperative care decisions and preferences for participation in decision making roles.

Postoperative Care Decisions

The rank order of importance, from the patients' perspective, of participating in the nine postoperative care decisions was determined. The most remarkable finding from this endeavour was the consistency with which "activities to do and avoid doing at home" was scaled as the most important postoperative care decision in which to have input, irrespective of patients' gender, age, place of residence, education, coexisting illness, perceived outcome of surgery, and decisional role preferences and perceptions.

The time frame in which the data were collected may have had an effect on the selection of "activities to do and avoid doing at home" as the postoperative care decision that is most important for patient input. Patients were sampled within three days of discharge and could have been becoming concerned about how they would be managing at home. Had patients been sampled earlier in their postoperative period, a different decision may have had greater priority. In future studies, sampling patients at various times during their pre- and postoperative experience would be helpful in determining if and how patients change their priorities about participation in postoperative care decisions during the time trajectory.

A reason why patients may have selected "activities at home," is that patients may believe that medical knowledge is not required to make these types of decisions. If this were the case, Thompson et al.'s (1993) study provides the rationale. Thompson et al. determined that patients have a greater preference for participation in decision making when medical knowledge is not required. "Activities at home" may have more to do with the "lifeworld" (Mishler, 1984) of the patient than with medical knowledge. This topic includes information within the patient's field of authority. Also, at home, the patient sheds some of the traditional sick role behaviours (Parsons, 1974) and resumes more self-care responsibilities. These responsibilities include continuing to enhance the recovery process. It is possible that, at home, people take on more responsibility for resolving their health problems than they do when they are hospitalized. The shift to taking more responsibility for resolving their health problems can be interpreted as a shift from the medical model in the hospital to the compensatory model at home (Brickman et al. 1982).

If involvement of patients in postoperative care decision making is to be fostered, three days from discharge might be a good time to begin involving patients about decisions about their home activities. Providing patient education through individual communication and providing individualized printed material would be appropriate. The making of individualized printed material should not be a problem in this day of computer sophistication. General forms could be used and the nurse could add or delete information as appropriate. Timing is also a factor in patient education. These patients seemed to be interested in home activities and psychological help. Perhaps nurses and physicians should be discussing these topics with postoperative cancer patients within three days of hospital discharge.

Consistency of Subjects

Although all subjects were deemed statistically consistent in their selections of postoperative care decisions, there was a considerable amount of inconsistency in their comparative judgments. Edwards (1957) has provided four reasons for inconsistencies to occur. Disinterest in the task leading to carelessness was one reason. Patients who preferred an extreme passive decision making role may have been disinterested in the task of doing the paired comparisons about postoperative care decisions. To them, the selections may have been a senseless activity because of a belief that the health care providers only should be making these decisions. It is interesting that they continued to perform the task given their preference for passivity. This was probably an example of patients "toeing the line" as described by Waterworth and Luker (1990). The validity of the paired comparisons of patients who preferred the most passive role in postoperative care decisions is extremely questionable. All patients appeared to be interested in sorting the cards to determine their preferred surgical treatment decision making role.

Because the relevance of the task of making paired comparisons about the importance of participating in postoperative care decisions was questionable in patients who preferred passive roles in decision making, the validity of passive patients' ranking of postoperative care decisions is questionable. Although there were several significant differences in the ranking and clustering of postoperative care decisions in various categories of subjects, the questionable validity of passive patients' scores nullifies the clinical significance of these differences. Because validity of passive patients' rankings of postoperative care decisions are questionable, and more than a quarter of the sample preferred a passive postoperative care decision making role, no discussion of relationship of postoperative care decision rankings to learning needs, nor factors that are associated with the ranking of postoperative care decisions will be provided.

The small sample size of this study did not allow sufficient numbers of active decision making patients to be further analyzed to determine the effect of demographic or other factors on the ranking of postoperative care decisions. As well, no analysis on the basis of type of cancer or type of surgery was carried out due to small numbers of patients in each category and the lack of availability of pathology reports on the ward in a 54% of the cases. In future studies, sufficiently large sample sizes of patients who assume active decision making roles should be collected so that these analyses can be made.

Edward's (1957) second reason for inconsistencies in Thurstone scales is that stimuli may be so similar that judgments are difficult to make. Postoperative care decisions about analgesic dose and time of administration are closely related. One patient stated, quite reasonably, that participation in either of these could result in the same thing and it was therefore difficult for her to decide which was more important. Several patients made verbal and nonverbal indications of difficulty when they were required to choose between analgesic dose or time. Several subjects voiced difficulty in determining the difference between treatment decision roles B and C. The formation of role categories that took this into consideration ameliorated some of the problem.

If stimuli have attributes or dimensions other than the one in which the researcher is interested, subjects may not view them along the single dimension on which scaling is being attempted. This was Edwards' (1957) third reason for inconsistencies. All postoperative care decisions could be ranked in order of importance to be made rather than importance for participation in the decision making process. This may have occurred even though the researcher attempted to counteract this possibility by verbally explaining that the decisions were not to be judged in order of importance to be made but were to be considered only according to importance for their participation in the decision making process. From the verbalizations made by some subjects, it was difficult to tell if they were truly making their judgments based on the attribute of the researcher's interest. An improved version of the wording might be: If participation in making a decision in your postoperative care were offered to you, in which one of the following pairs of decisions would you prefer to participate most?

When selecting preferred surgical treatment decision roles, the statements on the cards used in the card sort did not have the word surgical. Some patients had to be reminded that the treatment under investigation was the surgery they had recently undergone rather than future treatment (chemotherapy or radiation therapy) for their cancer. When further research is done on surgical decision making and Degner and Sloan's (1992) treatment decisional role cards are adapted, the word surgical should be inserted in the statements.

The propensity of some people to have a general personality trait of being inconsistent was the fourth reason given by Edwards (1957) for inconsistent responses to occur. No measures were taken to determine subjects' propensity to be inconsistent. Therefore the representation of people in the sample with a propensity to be inconsistent is unknown.

Edwards' (1957) formula for determining the maximum number of circular triads which is used to judge the consistency of subjects in rating their choices, appears to be flawed. According to Edwards' formula, the maximum number of circular triads that one subject can commit, for nine stimuli, is 30. The subject is deemed to be inconsistent only if more than 27.2 circular triads are committed. However, the computer generated a possibility of 84 circular triads for nine stimuli. Therefore the basis for the formula in determining consistency of subjects is flawed. Although 16% of subjects each committed 15 or more circular triads, they were deemed consistent by this test. Therefore the validity of the statistical test in questionable.

Sureness of Choice

The span of the z score range is an indication of sureness of choice. A narrower span indicates less self confidence than a wider span. No category of patients had a wide span. When ranking the postoperative care decisions is not a relevant task for patients, a narrower span of z scores would be expected. Therefore the slightly narrower span of z scores obtained by patients who preferred passive surgical roles when ranking postoperative care decisions is not surprising. Patients who preferred passive surgical decision roles had a slightly narrower span of z scores in the postoperative care decisions than those who preferred active-collaborative surgical decision roles.

Patients who assumed a passive role in surgical treatment decision making had a slightly wider span of postoperative decision z scores than patients who assumed an active or collaborative role in surgical treatment decision making. Patients who assumed a passive role in postoperative care decision making had a narrower span of postoperative care decision z scores than patients who assumed active or collaborative roles in postoperative care decision making. It is difficult to explain why there are inconsistencies in these results. Perhaps other variables that could not be separated out due to small sample size, were exerting an effect (Wilson, 1985).

Patients' uncertainty about prioritizing postoperative care decisions appeared to be underlined when the decision selected from one of nine statements as most important in which to participate (psychological help) was not the same decision as Thurstone's scaling indicated as most important (activities at home). However, upon closer examination, the frequency distribution of the "pick one" set was very similar to the ranking obtained using Thurstone scaling procedure. The postoperative care decision clusterings at the top of the ranking were the same. The two most favoured postoperative care decisions were "activities at home" and "psychological help." Patients were capable of identifying, from a list of postoperative care decisions, the one in which participation was most important for them. Since the results of the 36 paired comparisons and the "pick one from a list of nine" were similar, the pick one procedure could be used for patients in further research who might be too fatigued or weak to complete the paired comparisons questionnaire.

Preferred Surgical Decision Making Roles

Thurstone's Law of Comparative Judgement was also used to rank the surgical decision making roles. In Degner and Russell's (1988) description of the theoretical dimension for decisional control, 65% of the patients followed the theoretical dimension. A similar proportion was found in studies conducted by Degner and Sloan (1992). In this study, 66% followed the theoretical dimension. Therefore the existence of a theoretical dimension of keeping, sharing or ceding decision making control is supported.

The majority of patients preferred passive roles in this study. Similar results were found by Degner and Sloan (1992) and by Sutherland et al.(1989) in patients with various types of cancer and by Davidson (1993) in prostate cancer patients. These results differed from Bilodeau's (1992) and Hack et al.'s (1994) studies of breast cancer patients and from Llewellyn-Thomas et al.'s (1995) study of patients with colorectal cancer. All of the studies used a similar scale to measure role preferences for treatment decision making and all patients were from Canada. The results of this study may have been different from Bilodeau's and Hack et al.'s results because women tend to prefer more decision making control than men (Thompson et al., 1993) and because there has been a great deal of media attention devoted to breast cancer issues. Also since women tend to seek more information than men (Marcus et al. 1993), they may have gained more medical knowledge about their disease and its treatment. The increased media attention provided greater opportunity for women to become informed about some of the issues in breast cancer treatment perhaps before they were diagnosed. Increased medical knowledge could have been a factor in increasing preferences for decision making control (Ende et al., 1990). The patients in this study had a variety of different cancer cites, and in that manner were similar to the patients in Degner and Sloan's and in Sutherland et al.'s studies. This studies' similar results with the same population attests to the validity and reliability of the tool and points to the assumption that Canadian cancer patients, in general, prefer a passive role in treatment decision making. However, Canadian cancer patients may be in transition to preferring more decision making control. The Llewellyn-Thomas et al. study was the most recent. Only a third of their patients preferred passive roles. It may be that Canadians are becoming more consumerist oriented with the passage of time and our proclivity to be influenced by the United States.

Direct comparison of Canadian to American cancer patients, role preferences for treatment decision making cannot be made because of dissimilarity in the measurement tools. The qualitative studies done in England (Avis, 1994; Meredith, 1993; Waterworth & Luker, 1990), in Manitoba (Degner & Beaton, 1987), and in the United States (Fisher, 1988) leave the impression that American patients are more consumer oriented in their health care preferences and behaviours.

Patients in this study had the same preferences for keeping, sharing, or ceding decision making control for deciding about surgery and deciding about postoperative care. Patients' preferences for participation in deciding to have surgery would be helpful information for surgeons to pass along to nurses when patients are admitted to hospital. If decision making role preferences are known in advance, those who prefer collaborative and active roles might have an improved chance of achieving their preferred roles. Physicians' assessments of the decision making role preferences of their patients could be forwarded with other information about the client.

Achievement of Preferred Surgical Decision Roles

Patients who preferred active/collaborative surgical decision making roles were greater in number than those who assumed active/collaborative surgical decision roles. The results of this study differ from Sutherland et al.'s (1989) with respect to achievement of preferred decision making roles. There were no significant differences between "ideal" and "actual" roles in Sutherland et al.' study. There are several possible reasons for the differences between this study and Sutherland et al.'s. Sutherland et al's (1989) subjects were outpatients receiving post-surgical cancer treatments. In this study, patients were hospitalized and recovering from surgery. Outpatients have more control over their activities of daily living and live in a less threatening environment than hospitalized patients do. Postoperative patients may also believe that they are the "work objects" of their care givers (Avis, 1994). These factors may have constricted the postoperative cancer patients' view of their participation.

Sutherland et al. (1989) commented that patients in their study were exposed to an array of educational opportunities. Perhaps, in the Sutherland et al. study, patients' ease of obtaining information allowed those who preferred a collaborative role to achieve it because their information needs were satisfied. The patients in this study, perhaps, had less educational opportunities than those in Sutherland et al.'s study. In the Sutherland et al. study, patients who were more active in seeking information and in Hack et al.s (1994) study, patients who preferred more information were associated with collaborative or higher decision making roles rather than passive decision making roles. In this study, patients who assumed collaborative decision making roles identified more discharge information needs than passive patients. However, there was no difference in information needs between patients who preferred passive or active-collaborative decisional roles. These comparisons underline the need to provide patients with the opportunity to obtain information so that they can enact a collaborative role if they so wish. However, at this point, there is no answer to the question: Did postoperative patients in this study who wanted to participate in decision making receive sufficient information to allow them to participate at their desired level?

Given that: (a) The majority of cancer patients want maximal information (Brandt, 1991; Cassileth, Zupkis, et al., 1980; Hack et al. 1994). (b) Possession of medical knowledge (Ende et al. 1990) and higher levels of education (Thompson, 1993) are associated with increased preference for participation in treatment decision making. (c) In all except studies using those using the HOS (King et al., 1987; Wallston et al., 1987), positive or neutral outcomes have been associated with participating in treatment decision making (Brody et al., 1989, Fallowfield et al. 1990; Hillmann, 1994; Levy, Herberman & Lee, 1989; Morris & Ingham, 1988; Morris and Royle, 1988). Therefore it is appropriate to provide patients with easy access to medical information. Those who prefer to seek information and participation in treatment decision making are enabled to do so; those who cope by avoiding information have the option of not obtaining it.

Nurses have endorsed patient teaching. It has demonstrated improvement in patient compliance (Williams et al., 1988), allowed for early discharge (Edwards et al., 1988) and has been associated with better patient outcomes (Devine & Cook, 1986). However, nurses rely mainly on information giving and advice giving both of which are not highly effective (Zylinski, 1993). Learning is usually more effective when the learner is actively involved rather then a passive recipient.

Shaw et al. (1994) explored the influence of information on the breast biopsy experience. Patients' uncertainty about the possible outcome led to feelings of distress. The major strategy that they used to reduce their distress was to control the amount and type of incoming information. Postoperative cancer patients who are waiting for the results of pathology reports may be doing the same. If they do not obtain the results of their pathology reports before they are discharged from the hospital, they may not be in a state of readiness to receive information they will need before they are discharged. Therefore, even if the postoperative patients in this study were exposed to educational offering, they may not have taken advantage of those opportunities.

Patients who preferred and assumed the most passive role personified the traditional sick role described by Parsons (1975). They had willingly relinquished their right to make decisions about their treatment. Patients who preferred to have some input into decision making had not completely relinquished their well role or their rights. Unfortunately there was a significant number of patients who preferred to have collaborative-active roles but instead assumed passive roles. The reasons for this situation must be examined.

Health care providers may be acting more paternalistically than their patients who want to participate in health care decision making would prefer. Have patients' preferences for participation been appropriately assessed? Strull et al.(1984) found that practitioners were significantly poor at estimating both information and decision role preferences. Leinster (1994) has suggested that it is easy to infer a patient's preferred role based on the patient's behaviour. However, even though patients may prefer to participate they often do not voice their desire (Beisecker, 1988; Brody et al., 1989). It would appear that more attention should be paid to appropriately assessing the patient's preferred decision making role.

Are health care practitioners ready to accept patient participation in treatment decision making? Physician manipulation of information to ensure control of the patient-physician relationships has a long history and it still seems to be in effect (Meredith, 1993; Miyaji, 1993). When Szasz and Hollender (1956) first described patient-physician relationships, the mutual participation model was almost never practised. Some physicians are still not been enthusiastic about endorsing it (Meredith, 1993). Physicians firmly believe that they should have control of treatment decision making (Beisecker et al., 1994)

Are patients receiving sufficient and appropriate information and emotional support to be become less intimidated and more in charge of their beings in order to participate in treatment decision making? Comments made by passive patients in this study indicated that they did not have enough information to participate in treatment decision making. Instead they trusted that their physicians would make the appropriate decisions for them. Patients who assumed less than their preferred level of participation in surgical treatment decision making cited insufficient information provided, emotional difficulties, lengthy waiting periods, and the need to make decisions in a hurry as hindering factors. Busby and Gilchrist (1992) found that during medical rounds, patients received little explanation and they had a great deal of difficulty understanding the discussions that were about them. Leinster (1994) described how breast cancer patients in his practice are provided with information, emotional support, and time to make surgical decision with the help of specially trained breast nurses.

These are questions that health care providers should be asking of themselves when they care for patients. They are also questions that should be addressed in future research. The proportion of patients who prefer an active or collaborative role is expected to increase in the future due to increased expectations generated from a more informed public and the continued effects of the consumer movement.

Traditional paternalistic behaviours may need to be modified so that patients who wish to participate in treatment decision making are given the appropriate information and support. Impediments to patient participation in decision making need to be identified and removed. Although most patients in this study felt they had obtained all the information they wanted, access to information in a form that was understandable was an issue to some who wanted more input in decision making than they achieved.

Not inviting patient participation in decision making may be impeding the patient who wishes to take a collaborative role in treatment decision making. If patients do not know that their participation is allowed and welcomed, they will behave like the passive patients described in the Waterworth and Luker (1990) study. When patients prefer a passive role in treatment decision making, they do not acknowledge and value their own knowledge. In paternalistic decision making, practitioners to not acknowledge and value patients' knowledge. "The voices of the lifeworld" (Mishler, 1984), that the patient is capable of bringing to decision making process are not viewed as relevant. The extremely passive patients in this study seem to have the mind set described by Avis, (1994). They were in hospital to be worked on, therefore, they believed that they should not take part in the decision making process. They did not believe that their knowledge of themselves was relevant to postoperative decisions. They placed faith in their physicians that appropriate decisions would be made on their behalf. Passive patients were deeply entrenched in the medical model.

Most of the patients in this study trusted their physicians to make the right decision for them. Some patients did not have much trust in their nurses. Patients need to establish rapport with one surgeon but with a multitude of nurses. Lack of continuity of care by nurses appeared to be an obstacle to the development of trusting nurse-patient relationships. In cases where the patient identified a problem in the relationship between the care-giver and the patient, there was also an inability to obtain the preferred decision making role. Staffing patterns and methods of delivery of nursing care effect continuity of care and nurse-patient relationships. Unit managers and researchers might want to look into finding ways to improve patient assumption of preferred decision making roles and assisting patients to resume the decision making role they preferred before they were ill by making changes to improve continuity of nursing care.

When this researcher was obtaining informed consent, some of the subjects remarked that the idea of participating in the decision making process was novel to them. Informed consent implies participation in decision making (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982). Hearn (1992) indicated that exercising therapeutic privilege should occur only in exceptional cases. Did informed consent occur in cases where the patients expressed that the idea of being invited to participate in treatment decision making was novel? Had these patients given away their prerogative to participate in treatment decisions or had it been withheld from them? In future studies, patients might be asked if they were invited to participate in treatment decision making.

Factors Associated with Differences in Decision Role Preferences

Demographic Factors

Decision role preferences have been associated with demographic factors (Beisecker, 1988; Blanchard et al. 1988;

Degner & Sloan, 1992; Ende et al. 1989; Thompson et al. 1993). Demographic factors were also associated with differences in role preferences in this study. The majority of patients in all categories preferred passive roles. However, men were more passive than women, patients 65 years and older were more passive than younger patients, patients who had not graduated from high school were more passive than those with more education and patients who resided in Winnipeg were more passive than those who did not reside in Winnipeg. Men, older patients, and those with less education all preferred extremely passive roles, as was the case in other studies (Beisecker, 1988; Blanchard et al. 1988; Degner & Sloan, 1992; Ende et al. 1989; Thompson et al. 1993). The proportion of patients who followed the theoretical dimension preference orders in this study were the same as the cancer patients in Degner and Russell's (1988) and similar to Degner & Sloan's (1992) study. All demographic differences except place of residence had the same effects that were found by Degner and Sloan (1992).

The majority of older patients, patients with less education, and residents of Winnipeg in this study were more sure of their preferred decision making role: to be passive. Perhaps patients who were attempting to participate in decision making roles were receiving less encouragement or support to assume this role and therefore were not as self-confident. In recent years women with specific type and stage of breast cancers have been brought into the decision making process to determine the type of surgery (Leinster, 1994). Perhaps the extra information and support given to women in making these decisions was the reason why the majority of women were more sure about their preferred decision making role and wanted greater participation than men.

In this study, there were 13 mastectomy patients and two lumpectomy patients. The role preferences of breast cancer patients did not appear to be different from other patients in this study. Breast cancer patients who choose mastectomy are more likely to follow their surgeon recommendations significantly more than those who choose lumpectomy (Deming, 1989). This may be the reason why the breast cancer patients in this study preferred less input into decision making than did the breast cancer patients in Bilodeau's (1992) and Hack et al.'s (1994) studies. It is possible that under representation of lumpectomy patients in this study had effected the results. One reason why lumpectomy patients were under represented in this study is because most lumpectomy patients were treated on the unit where few patients were recruited. Their short hospital stays and the extended time for pathology reports to be delivered to the nursing units, interfered with recruiting lumpectomy patients into this study.

Coexisting Illnesses

Patients with coexisting illnesses formed a group who preferred a more passive role. Two reasons are suggested for their preference for being more passive than those without coexisting illnesses. (a) These patients may have had more to cope with than those without coexisting illnesses and may present as being more ill than patients without coexisting illnesses. (b) It may be the case that patients with coexisting illnesses have more experience in the patient role. Studies indicated that in cases of more severe illness (Ende et al. 1989) and in cases where the subjects are also patients (Ende et al., 1990), less decision making control is preferred. The results of this study lend support to Ende et al.'s (1989, 1990) findings.

A greater preference for a passive role in patients with coexisting illnesses may have resulted from previous experiences with health care providers while undergoing diagnosis and treatment for previously diagnosed concerns. Health care providers' propensity to make decisions "for" rather than "with" patients may have conditioned patients with coexisting illnesses to prefer and assume more passive decision making roles than those without coexisting illnesses. Patients may be accepting a passive role in decision making because passive patient behaviour has been expected by health care providers (Beisecker et al., 1994, Meredith, 1993). Assuming passive decision making roles when more active roles are preferred may be examples of patients "toeing the line" (Waterworth and Luker, 1990). Patients' previous experiences with illnesses and/or the health care system may have increased their feelings of intimidation if previous attempts at taking a more consumerist role had resulted in physicians behaviours that prevented patients from obtaining the information they felt they needed (Fisher, 1988). In this study, patients who had coexisting diseases were very passive. Further research is needed about the relationship of decisional role preferences and feelings of intimidation related to illnesses and/or the health care system.

Coping

Vachon and colleagues (1990) indicated that most Manitoba cancer patients are highly stressed and in need of psychological assistance to cope with the situation when first diagnosed and when dealing with the aftermath of surgical treatment. Although no measurement of psychological coping and adjustment was conducted in this study, the researcher sensed that many of those who preferred active and collaborative roles displayed less anxiety and seemed to be coping with the situation better than many who preferred a passive role. Patients who preferred active or collaborative decision making roles generally appeared more self-confident. Also, they displayed less evidence of denial of their health situation in that collaborative decision makers in this study were less likely to indicate that the surgery had cured them of their cancer. An increased preference to give away decisional control may reflect psychological stress. Denial of information and emotional distress are barriers to comprehension (Eden, Black & Emery, 1993).

Research about the relationship of patient collaboration in decision making has usually indicated positive or neutral patient psychological outcomes. Research about the relationship of stress, effectiveness of coping strategies and preferences for information has indicated that information has a positive effect for those who cope by seeking information. Barsevick and Johnson (1990) found that, in colposcopy patients, information seeking was associated with having confidence and it was not associated with fear, anger or depression. In this study, patients who assumed active-collaborative decision making roles had more pre-discharge information needs. The relationship of treatment decision role preferences, effective coping and experience in the patient role needs to be examined so that we can more completely understand their effect on patients with life threatening illnesses.

Patient Perception of Surgical Outcome

Differences were observed in treatment decision making roles between patients whose beliefs about the outcome of the surgical procedure were overly optimistic and those who were realistically unsure. "Unsure" patients had a greater preference to have some participation in treatment decision making than those who believed they had been cured by the surgical treatment. As a group, "cured" patients preferred the most passive role in treatment decision making and had the same preference orders for participation in decision making as the majority of cancer patients in Degner and Sloan's (1992) study, whereas the "unsure" group of patients preferred roles D, C, and B more than E. The "cured" patients were somewhat more decisive about preferring a passive decision making role as evidenced by the somewhat wider range of z scores when preferred surgical treatment decision roles were scaled. Being "cured" was either a coping mechanism, a reflection of being given information in an overly optimistic way, or it could be that "cured" patients were less critically examining information that was inconsistent with the preferred outcome of being cured (Ditto & Lopez, 1992).

The percentage of patients with overly optimistic beliefs about the outcome of the surgery was similar to Mackillop et al.'s (1988) findings. Patient perception of being cured may have been affected by verbal reports made to them about "all going well during surgery" and from over generalizations of comments about their "good" postoperative recovery. Believing surgery had cured the disease may have been a coping strategy that was used to deal with the psychological stress these patients were enduring. Fostering an optimistic belief about the surgical outcome while waiting for pathology reports may have been a cognizant or inadvertent action by physicians when informing patients about the surgical procedure performed and/or recovery from it.

Encouraging patients to adopt or maintain an optimistic perspective while waiting for pathology reports may help patients maintain hope. However, encouraging optimism without addressing the uncertainly of the situation may have detrimental effects. Protecting patients from uncertainty does not help them learn to deal with it effectively. Nor does it help them cope when bad news is received as evidenced by the patient who stated he was first told everything was alright and then was told this was not the case after the pathology report arrived. Paternalistic behaviour of care givers in the medical model fosters dependency rather than helping patients retain or regain their independence (Brickman et al.,1982). Assisting the patient to deal with the uncertainty of the situation rather than shielding them from it may help develop coping skills that will be required to deal with continued uncertainty during follow-up testing and treatment.

Preference for taking an active role in treatment decision making may have been diminished by patients' difficulties coping with the cancer situation. There was a greater percentage of inaccurate perceptions of reality of the surgical outcome and a greater preference for taking a passive role in decision making in the "cured" group than the "unsure" group. A more accurate perception of reality and a less passive preference for participation in decision making may be an indication that the "unsure" group was coping with the situation better than the "cured" group. Facilitating collaborative decision making may help patients cope with the ongoing stress of having cancer.

Information Needs

The relationship of information needs to coping was discussed in an earlier section. Although there was a ceiling effect in some areas of the information needs scale, patients who assumed active/collaborative surgical treatment decision making roles identified a greater need for information than patients who assumed passive decision making roles. Perhaps patients who were able to assume an active/collaborative role had to actively seek information and/or were more cognizant of the benefits of obtaining information than other patients. Research that discovers differences between the ways in which active-collaborative and passive patients obtain information may indicate how care-givers can be more effective in the manner in which information is given. Research that examines differences in the actual content of information that is obtained by active-collaborative and passive patients would help care givers provide the appropriate type of information that is needed by patients who prefer to take active-collaborative or passive role in treatment decision making.

Recommendations for Further Research

Recommendations for further research are embedded throughout this chapter. These will be summarized at this point. In future studies, sampling patients at various times during their pre- and postoperative experience would be helpful in determining if and how patients change their priorities about participation in postoperative care decisions during the time trajectory. Does the amount of responsibility hospitalized patients prefer and assume change after they are discharged?

Summary

Although there are considerable limitation to this study due to methodological problems and sample size, three important findings emerged from this study. First, patients who prefer active or collaborative decision making roles were less likely to assume their preferred roles than patients who preferred passive decision making roles.

Secondly, the majority of patients, irrespective of age, gender, education, presence of coexisting illness, place of residence, perceived outcome of surgery and decisional role category selected "activities to do and avoid doing at home" as the most important postoperative care decision in which to have input. Thirdly, when patients were asked to pick one from a list the postoperative care decision in which their participation was most important, the resulting frequency distribution was similar to the ranking of postoperative care decisions using Thurstone's paired comparisons scaling. These findings can be utilized in further research.

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Appendix A

Letter of approval from the University of Manitoba School of Nursing Ethical Review Committee.

The University of Manitoba

SCHOOL OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#91/14

Proposal Title: "Surgical Cancer Patients' Preferences for Information and Decision Making Control."

Name and Title of Researcher(s):
Deanne Rhonda Spiegel
Master of Nursing Graduate Student
University of Manitoba School of Nursing

Date of Review: June 03, 1991.

APPROVED BY THE COMMITTEE: JUNE 03, 1991.

Comments:

Date: June 11, 1991

Erna J. Schilder, RN, DNS
Chairperson

Associate Professor
University of Manitoba School of Nursing
Position

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 91/01/11/se

Appendix B

Explanation to Patients / Consent Form

SURGICAL CANCER PATIENTS' PREFERENCES FOR INFORMATION AND DECISION MAKING CONTROL

You have been invited to participate in a study to find out your preferences for information and for control in making decisions about your medical care. I am Deanne Spiegel, a student in the Master of Nursing Program at the University of Manitoba. I am conducting a research study for the basis of my thesis. Dr Lesley Degner is my thesis supervisor. From this study we hope to learn more about patients' preferences for obtaining information about their illness and its treatment and for participating in medical decision making. Also, we hope to learn about patients' perceptions of the effect of nursing behaviours on patients' ability to obtain information and to participate in decision making. The particular patients that we wish to learn about are those who have had surgery for the treatment of recently diagnosed cancer. The results of this study will be useful in improving the quality of nursing care given to these patients. Between 60 to 100 other patients who have had surgery for treatment of cancer will be asked to participate in this study.

If you decide to participate in this study, you will be asked permission to obtain information from your chart, to fill out two questionnaires, to select cards which picture various doctor-patient relationships, and to answer some questions. Both questionnaires can be answered mostly by circling the answer. Each questionnaire will take approximately 15 minutes to complete. Should you need assistance in completing the questionnaires, I will help you. After the first questionnaire is completed, you will be asked to identify the decision making relationship with your doctor that you prefer. A set of five cards, with each card describing a different doctor-patient relationship in the decision making process, will be used. You will be asked to identify the card which most closely shows the relationship you preferred to take in deciding to have your operation. I will then ask you to identify the card which most closely pictures the decision making relationship that actually occurred when this decision was made. You will also be asked to indicate your preferred relationship with your doctor or nurse in making a decision about the care given to you after your operation. I will then ask you to identify the card which most closely pictures the decision making relationship that actually occurred when this decision was made. The card choosing procedure will take approximately 10 minutes. You will then be asked to

complete the second questionnaire. Then I will ask you what has been helpful and what has hindered your obtaining information and having your opinions considered in decision making. I will take notes during the interview. The interview will take approximately 10 minutes. The total time required is
approximately one hour. There are no known risks associated with your participation in this study.

All information which you provide will be confidential. If a private room is available, it will be provided for you to complete the questionnaires, the card sorting procedure and the interview. Your name will not be on any written materials. To assure anonymity, you will be identified by a code number only. Information obtained as result of your participation in this study will be kept in a locked cabinet to which only the investigator has the key. The consent forms will be kept separate from the questionnaires and interview forms. The results of this study will be sent to the researchers who designed one of the questionnaires that was used to help them refine the questionnaire. Also the results of this study may be submitted for publication in a nursing or other professional journal.

Your decision whether or not to participate will not effect your care or your relations with the staff of the hospital. You may discontinue participation at any time or refuse to answer any of the questions without consequences.

If you have any questions, please feel free to ask. I can be contacted by telephone at or Dr. L. Degner can be contacted at . If you so desire, a summary of the study results will be made available to you.

________________________ ____________

Signature Date

________________________ ____________

Signature of Investigator Date

Appendix C

Letter Requesting Permission to Conduct Research at St. Boniface General Hospital

Deanne Spiegel

Winnipeg, Manitoba
R
May 17, 1991.

Dr. E. Adaskin
Director
Department of Nursing Research
St. Boniface General Hospital
Winnipeg, Manitoba

Dear Dr. Adaskin

I am writing to request permission to conduct a study of recently diagnosed adult postoperative cancer patients within three days of their expected discharge from hospital to determine their information needs, information seeking styles and preferences in decision making. Assessment of the patients' perception of learning needs, determination in which decisions patients prefer to participate and their preferred role in decision making will assist in assessing the need for and development of psychoeducational programs to meet cancer patients learning needs. A recent survey of Manitobans living with cancer indicated that many have their greatest problems at the time of diagnosis and surgery. These problems may be improved through social support and psychoeducational intervention.

I am Deanne Spiegel, a graduate student in the Master of Nursing Program at the University of Manitoba. This study will the basis for my thesis. My thesis committee members are Dr. Lesley Degner (chair), Dr. Erna Schilder (member), and Dr. Barry Anderson (external member). I would like permission to invite patients admitted to the St. Boniface General Hospital who are eligible for enrolment in this study to answer questionnaires and be interviewed. I hope to collect the data over a three month period beginning in June, 1991. Enclosed is an application form, an executive summary and a five page summary of my research proposal, consent form, questionnaires and interview guideline.

The questionnaires are designed to be self administered but I plan to be available to each patient should assistance be needed in completing them. The data collection procedure will take approximately 50 minutes to complete. Patients who will be invited to volunteer will be fully appraised of their rights as human subjects. The proposal has been submitted to the University of Manitoba, School of Nursing Ethics Committee for approval. Only after ethical approval is received will data collection begin.

Dr. Degner has spoken to Ms. McMorris, Director of Surgical about this project.

Results of the study will be available to the St. Boniface General Hospital and a summary of the results will be available to the patients who participate. The results will also be shared with the Sunnybrook Health Science Centre, North York, Ontario as a condition of the contract for using the Patient Learning Needs Scale which has been copyrighted by them.

Should you wish to discuss this study with me, I can be reached at or . Thank you for your consideration.

Yours sincerely

Deanne Spiegel

Appendix D

Letters of Approval for Access to Patients at St. Boniface Hospital

Hôpital général St-Boniface General Hospital

July 23,1991

Ms. Deanne Spiegel

Winnipeg, MB R

Re: Access to SBGH Approval

Dear Ms. Spiegel:

I am pleased to inform you that your project:

> Surgical cancer patients' preferences for information and decision-making control

has been approved for access to St. Boniface General Hospital patients, according to the protocol you have outlined. Approvals have been received from Dr. R. Danzinger, Ms. D. McMorris, myself, and Ms. Jan Dick, VP Nursing.

Your findings will be of interest and value to SBGH, and we look forward to the knowledge it may add to patient care.

Please feel free to access the Nursing Research Space when you are on site. We will be happy to facilitate your project in any way possible.

Contact me at 235-3480 with any questions you have now or as the work proceeds.

Sincerely,

Eleanor J. Adaskin, RN, PhD
Director of Nursing Research

EA/mj

PS Please send us a summary
of your results when complete.
Good luck!

409 Taché, Winnipeg, Manitoba, Canada R2H 2A6
Tel (204) 233-8563 Fax (204) 231-0640

A Grey Nun Corporation/Une corporation des Soeurs Grises
Affiliated with the University of Manitoba/Affilié à l'Université du Manitoba

Hôpital général St-Boniface General Hospital

August 8, 1991

Deanne Spiegel

WINNIPEG, Manitoba
R

Dear Ms. Spiegel:

I am in receipt of your letter of August 2nd which discusses your request for access to our patient population in gynecology who have had surgical intervention such as hysterectomy. I have discussed your letter of request with Dr. Phillip Hall, Medical Head of the Department of Obstetrics, Gynecology and Reproductive Sciences at St. Boniface General Hospital, and he is in agreement. We would be pleased to grant you access to the patient population who would meet your criteria for entrance into your study, namely the hysterectomy patients on the gynecology unit.

I will be speaking to Dr. Bob. Lotocki, Service Chief on Gynecologic Oncology, as well as the head nurse on this unit and Kaaren Neufeld, Clinical Nurse Specialist for the unit.

We will look forward to your completion of this study and your sharing of the results with both our nursing and medical staff. I hope this provides you with the required information. If there are any questions that you need to discuss further, please do not hesitate to call me.

Yours sincerely,

Edith Parker
Nursing Director
Maternal Child Health

EKP/bjns

cc: Dr. Phillip Hall
Dr. Eleanor Adaskin, Director, Nursing Research

Appendix E

Executive Summary

SURGICAL CANCER PATIENTS' PREFERENCES FOR INFORMATION AND DECISION MAKING CONTROL

Investigators: Deanne Spiegel (Thesis Researcher), Dr. Lesley Degner (Thesis Advisor), Dr. Erna Schilder (Thesis Committee Member), Dr. Barry Anderson (External Thesis Committee Member)

Purpose of the Study: The specific objectives of the study are: (1) to rank the order of importance, from the patient perspective, of participating in nine postoperative care decisions, (2) to determine if patients prefer to assume the same level of responsibility in deciding to have surgery as they do in making postoperative care decisions, (3) to determine if there is congruence between patients' preferred and assumed decision making roles, (4) to determine the relationship among patients' perceived information needs, preferred and assumed decision making roles and beliefs about being cured, (5) to explore patients' perceptions of the effectiveness of nursing behaviors in helping them attain their information needs and preferred decision making roles.

Sample: Data will be collected from recently diagnosed cancer patients who have undergone hysterectomy, prostatectomy, mastectomy or breast conserving surgery, gastric or intestinal resection, nephrectomy, pneumonectomy or lobectomy until 60-100 patients have been surveyed or a three month period elapses.

Setting: St. Boniface General Hospital surgical nursing units.

Procedure: (1) Patient demographic data forms will be completed. (2) The patient will complete a questionnaire which requires comparison of pairs of postoperative care decisions in which patients most want their opinions considered. (3) Using a 5 card sort procedure with each card depicting a different type of role patients could assume in treatment decision making, patient preference orders for decision making roles related to the decision to have surgery will be elicited. (4) From the five cards, the patient will point to the card that most closely approximates the his/her assumed role in deciding to have surgery, and preferred and assumed roles in making the postoperative decision selected by the patient as most important in having his/her opinion considered. (5) The patient will complete a questionnaire which assesses information needs. (6) A semi-structured interview with the patient will elicit data about the patient's attempts to obtain information and to participate in decision making.

Analysis: L. L. Thurstone's Law of Comparative Judgement will be used to rank the patient's perspective of nine postoperative decisions according to the importance of having the patient's opinions considered. Unfolding theory will be used to determine the preference order of decision making roles. Chi square will be used to compare differences among groups of patients who prefer and assume active, collaborative and passive decision making roles. Relationships among information needs, decision making roles and beliefs about being cured will be determined.

Appendix F

Demographic Data Form

ID. NO ______________________

Gender:

__________Male

__________Female

Age: (At last birthday)

____

Length of time since communication of diagnosis (days)

____

Type/Stage of Disease

____

Type of Surgery

____

________ diagnostic

________ curative

________ palliative

Co-existing illnesses

____

____

____

Place of residence

________rural (less than 30,000)

________urban (30,000 or more)

Appendix G

Data Collection Tool to Assess Preference for Participation in Postoperative Care Decisions

ID. NO. ____________

INSTRUCTIONS:

Please answer the following questions. If you have any difficulty in understanding what is asked, in deciding how to answer any question, or in recording your answers, please request my assistance. I will stay with you while you answer the questions or remain available to you, whichever you prefer. If you feel unable to complete the entire questionnaire and interview at this time, a later appointment may be scheduled for completion.

You may prefer to have a greater or lesser amount of participation in various day to day post operative care decisions that are made while you are recovering from your surgery in the hospital. Nine different postoperative care decisions which may have been made and in which you may want to have your opinions considered have been identified. The nine different postoperative care decisions have been paired with each other in all possible combinations. From the following pairs of decisions please circle the one which you believe is more important for your opinion to be included in the decision making process.

a. When I should get out of bed for the first time after surgery
b. Which foods should be served to me

a. When my dressing should be changed
b. What day I should be discharged from the hospital

a. How strong a dose of pain medication I should receive
b. What activities I should do and avoid doing when I go home

a. What time my pain medication should be given
b. If I should receive assistance in dealing with the psychological impact of my illness and surgery

a. If I should have a blood transfusion
b. When I should get out of bed for the first time after surgery

a. Which foods should be served to me
b. When my dressing should be changed

a. What day I should be discharged from the hospital
b. How strong a dose of pain medication I should receive

a. What activities I should do and avoid doing when I go home
b. What time my pain medication should be given

a. If I should receive assistance in dealing with the psychological impact of my illness and surgery
b. If I should have a blood transfusion

a. When I should get out of bed for the first time after surgery
b. When my dressing should be changed

a. How strong a dose of pain medication I should receive
b. Which foods should be served to me

a. What time my pain medication should be given
b. What day I should be discharged from the hospital

a. If I should have a blood transfusion
b. What activities I should do and avoid doing when I go home

a. If I should receive assistance in dealing with the psychological impact of my illness and surgery
b. When I should get out of bed for the first time after surgery

a. When my dressing should be changed
b. How strong a dose of pain medication I should receive

a. Which foods should be served to me
b. What time my pain medication should be given

a. What day I should be discharged from the hospital
b. If I should have a blood transfusion

a. What activities I should do and avoid doing when I go home
b. If I should receive assistance in dealing with the psychological impact of my illness and surgery

a. When I should get out of bed for the first time after surgery
b. How strong a dose of pain medication I should receive

a. What time my pain medication should be given
b. When my dressing should be changed

a. If I should have a blood transfusion
b. Which foods should be served to me

a. If I should receive assistance in dealing with the psychological impact of my illness and surgery
b. What day I should be discharged from the hospital

a. What activities I should do and avoid doing when I go home
b. When I should get out of bed for the first time after surgery

a. How strong a dose of pain medication I should receive
b. What time my pain medication should be given

a. When my dressing should be changed
b. If I should have a blood transfusion

a. Which foods should be served to me
b. If I should receive assistance in dealing with the psychological impact of my illness and surgery

a. What day I should be discharged from the hospital
b. What activities I should do and avoid doing when I go home

a. When I should get out of bed for the first time after surgery
b. What time my pain medication should be given

a. If I should have a blood transfusion
b. How strong a dose of pain medication I should receive

a. If I should receive assistance in dealing with the psychological impact of my illness and surgery
b. When my dressing should be changed

a. What activities I should do and avoid doing when I go home
b. Which foods should be served to me

a. What day I should be discharged from the hospital
b. When I should get out of bed for the first time after surgery

a. What time my pain medication should be given
b. If I should have a blood transfusion

a. How strong a dose of pain medication I should receive
b. If I should receive assistance in dealing with the psychological impact of my illness and surgery

a. When my dressing should be changed
b. What activities I should do and avoid doing when I go home

a. Which foods should be served to me
b. What day I should be discharged from the hospital

2. Please check the post-operative care decision which you believe is most important for your opinion to be included. Check only one.

____ When I should get out of bed for the first time after surgery
____ Which foods should be served to me
____ When my dressing should be changed
____ How strong a dose of pain medication I should receive
____ When my pain medication should be given
____ If I should have a blood transfusion
____ If I should receive assistance in dealing with the psychological impact of my illness and surgery
____ What activities I should do and avoid doing when I go home
____ What day I should be discharged from the hospital
____ Other (Please specify)________________________________

3. What was the date on which you were informed of your diagnosis?

____

4. What is the name of your illness?

____

5. Has your surgery cured you of your illness?

____ YES

____ NO

____ UNSURE

6. Please check the highest level of education you have obtained.

_____ grade nine or less

_____ some high school

_____ high school graduate

_____ trades certificate or diploma

_____ some university

_____ university graduate

Appendix H

Patient Learning Needs Scale

Code No ____

PATIENT LEARNING NEED SCALE

Introduction for Hospital Administration

Many people who are leaving the hospital have some questions about how to manage their care once they are at home. Different people have questions about different things. The following is a list of things which some people have said they would like to know to be able to take care of themselves at home.

For each of the following statements please circle the appropriate choice based on how important you think it is to learn about the area before you go home. If the item does not apply to your situation or illness please circle does not apply and go onto the next statement. If the item relates to you, your situation or your illness, please circle the appropriate number 1 through 5 with 1 having the least importance and 5 being extremely important for you to know.

IN ORDER TO MANAGE MY OWN CARE AT HOME I NEED TO KNOW:

		DOES NOT APPLY 0	OF NO IMPORTANCE 1	2	3	EXTREMELY IMPORTANT 4	5
1.	Which complication I should seek immediate help for?	0	1	2	3	4	5
2.	How to change my activities to save my energy.	0	1	2	3	4	5
3.	How each medication works.	0	1	2	3	4	5
4.	How to recognize a complication.	0	1	2	3	4	5
5.	What to do if I have trouble with my bowels?	0	1	2	3	4	5
6.	What a Home Care program provides?	0	1	2	3	4	5
7.	How to talk to family/friends about my illness.	0	1	2	3	4	5
8.	What to do if I have a reaction to a medication?	0	1	2	3	4	5
9.	Where I can get help for family to deal with illness?	0	1	2	3	4	5
10.	What complications might occur from my illness?	0	1	2	3	4	5
11.	How this illness will affect my future.	0	1	2	3	4	5
12.	When I can take a bath or shower?	0	1	2	3	4	5
13.	What symptoms may I have related to my illness?	0	1	2	3	4	5
14.	When can I start to do household activities safely.	0	1	2	3	4	5
15.	How to manage my pain.	0	1	2	3	4	5
16.	When to stop taking each medication.	0	1	2	3	4	5
17.	How much rest I should be getting.	0	1	2	3	4	5
18.	How to take each medication.	0	1	2	3	4	5

IN ORDER TO MANAGE MY OWN CARE AT HOME I NEED TO KNOW:

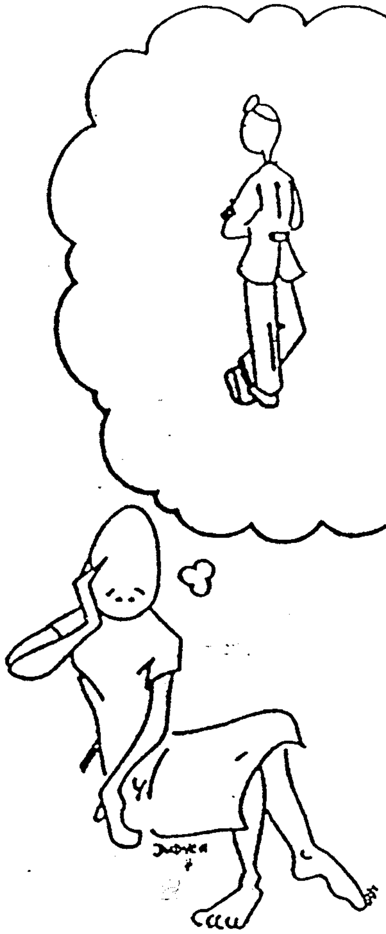
		DOES NOT APPLY 0	OF NO IMPORTANCE 1	2	3	EXTREMELY IMPORTANT 4	5
19.	Who will I see at my follow-up appointment?	0	1	2	3	4	5
20.	What the possible side effects of my treatment are.	0	1	2	3	4	5
21.	How to manage the symptoms that I might experience.	0	1	2	3	4	5
22.	How to get through 'red tape' in the health care system.	0	1	2	3	4	5
23.	Who my family members can call about questions of my illness.	0	1	2	3	4	5
24.	What caused my illness.	0	1	2	3	4	5
25.	How to care for my wound or incision.	0	1	2	3	4	5
26.	What to do if I have trouble urinating.	0	1	2	3	4	5
27.	How to prepare the foods I am allowed to eat.	0	1	2	3	4	5
28.	Which foods I can and cannot eat.	0	1	2	3	4	5
29.	What to do if I cannot sleep properly.	0	1	2	3	4	5
30.	What physical activities I cannot do such as lifting.	0	1	2	3	4	5
31.	How to get through 'red tape' to get services at home.	0	1	2	3	4	5
32.	Who to talk to about my concerns about death.	0	1	2	3	4	5
33.	How to care for my feet properly.	0	1	2	3	4	5
34.	Which vitamins and supplements I should take.	0	1	2	3	4	5
35.	Where I can get help in handling my feelings about my illness.	0	1	2	3	4	5

IN ORDER TO MANAGE MY OWN CARE AT HOME I NEED TO KNOW:

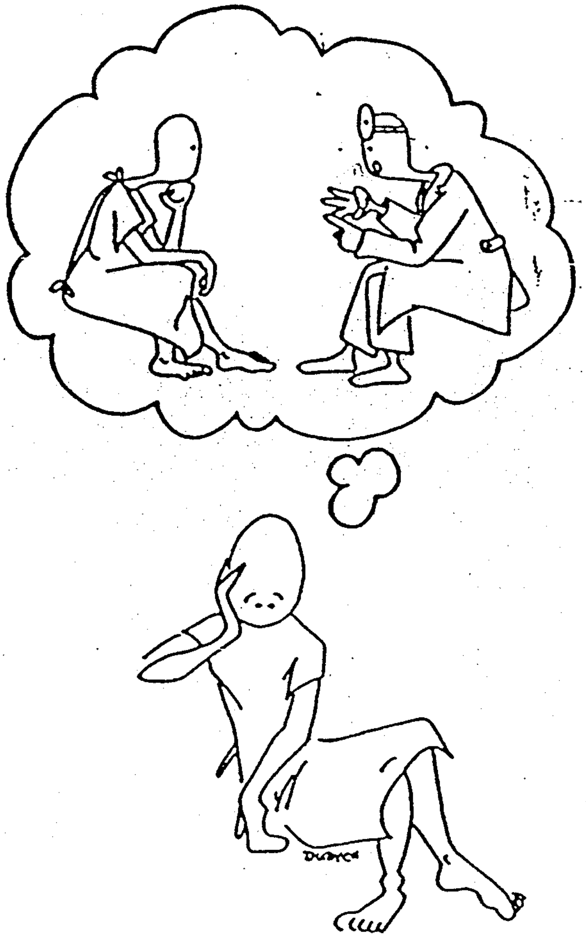
	DOES NOT APPLY	OF NO IMPORTANCE			EXTREMELY IMPORTANT	
	0	1	2	3	4	5
36. How to contact community groups for my health condition.	0	1	2	3	4	5
37. Why I need to take each medication.	0	1	2	3	4	5
38. How to prevent a complication from occurring.	0	1	2	3	4	5
39. The possible reactions to each medication.	0	1	2	3	4	5
40. How I can manage stress.	0	1	2	3	4	5
41. How to arrange transportation to follow-up appointments.	0	1	2	3	4	5
42. How to recognize my feelings towards my illness.	0	1	2	3	4	5
43. How to prevent my skin from getting sore.	0	1	2	3	4	5
44. When to take each medication.	0	1	2	3	4	5
45. Where I can get my medications.	0	1	2	3	4	5
46. How I can avoid stress.	0	1	2	3	4	5
47. What the purposes of my treatments are.	0	1	2	3	4	5
48. What physical exercise I should be getting.	0	1	2	3	4	5
49. How to prevent my skin from getting red.	0	1	2	3	4	5
50. How this illness will affect my life.	0	1	2	3	4	5

Appendix I

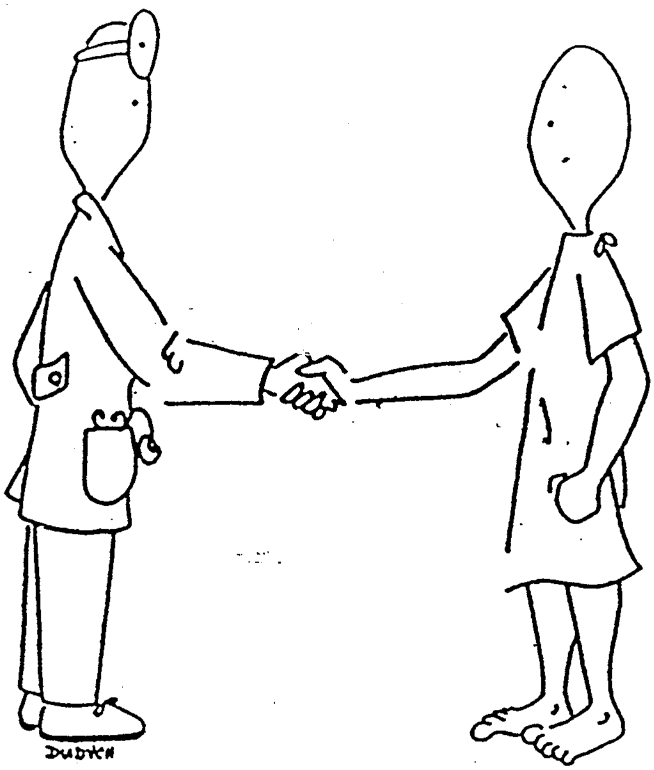
Photocopy of Degner's Cards Used to Determine Preferred and Assumed Surgical Treatment Decision Making Roles



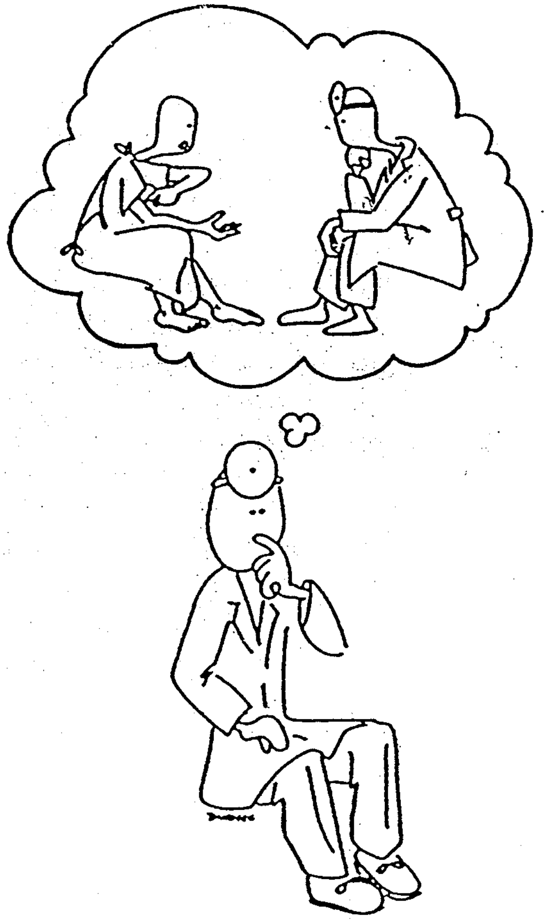
I PREFER TO MAKE THE FINAL SELECTION ABOUT WHICH TREATMENT I WILL RECEIVE.



I PREFER TO MAKE THE FINAL SELECTION OF MY TREATMENT AFTER SERIOUSLY CONSIDERING MY DOCTOR'S OPINION.



I PREFER THAT MY DOCTOR AND I SHARE RESPONSIBILITY FOR DECIDING WHICH TREATMENT IS BEST FOR ME.

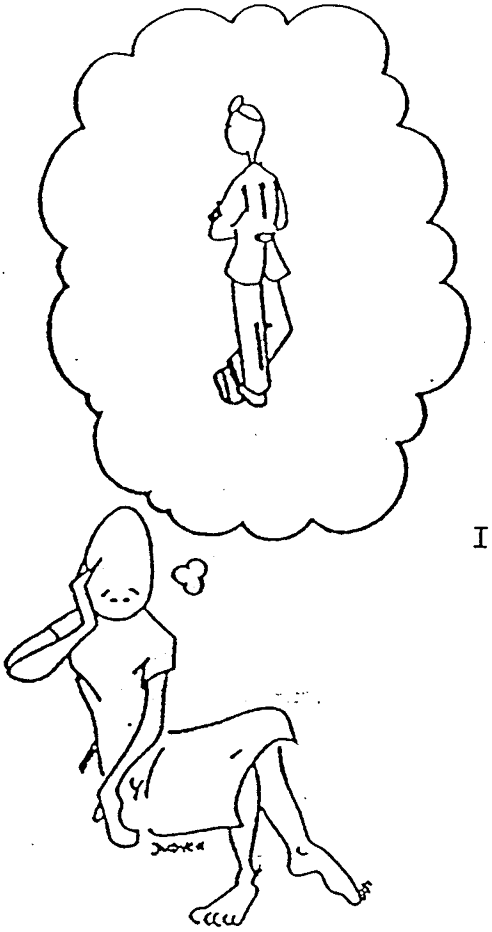


I PREFER THAT MY DOCTOR MAKES THE FINAL DECISION ABOUT WHICH TREATMENT WILL BE USED, BUT SERIOUSLY CONSIDERS MY OPINION.

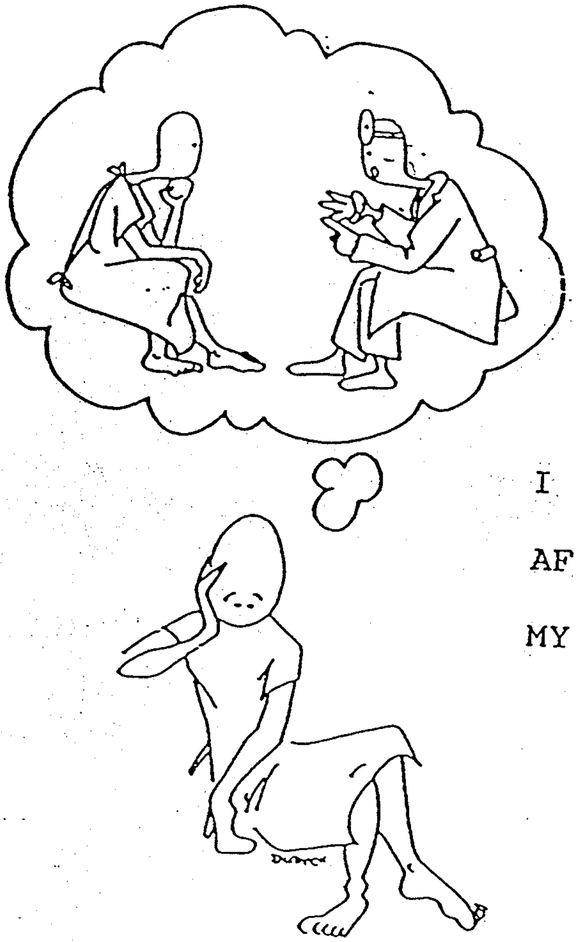
I PREFER TO LEAVE ALL DECISIONS REGARDING MY TREATMENT TO MY DOCTOR.

Appendix J

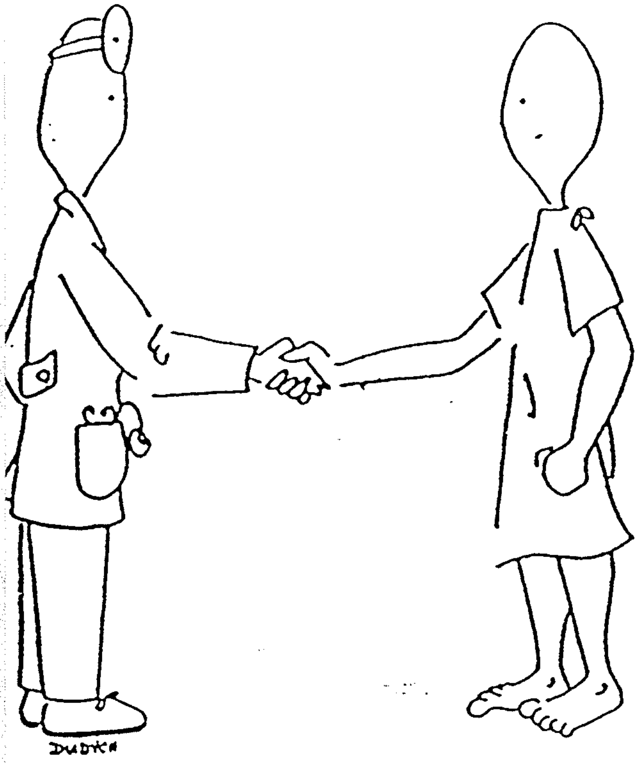
Photocopy of Cards Used to Determine Preferred and Assumed Postoperative Care Decision Making Roles



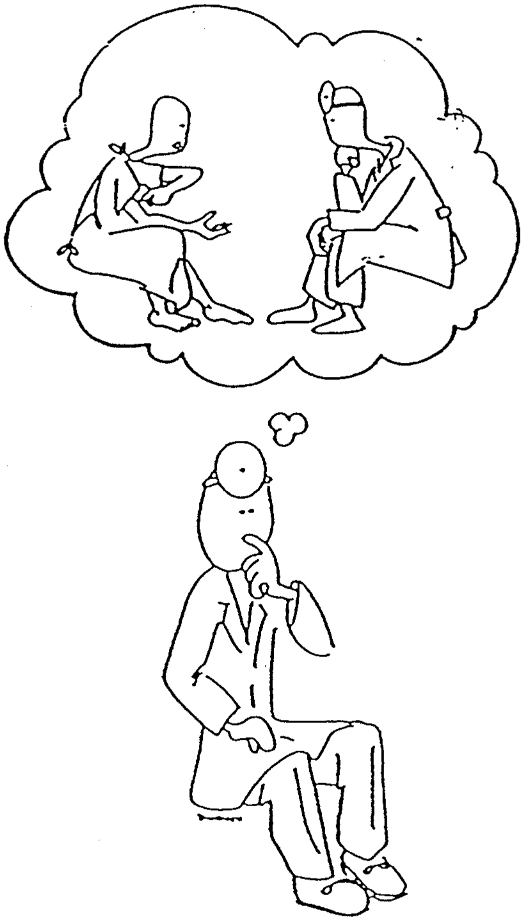
I PREFER TO MAKE THE FINAL DECISION.



I PREFER TO MAKE THE FINAL DECISION
AFTER SERIOUSLY CONSIDERING
MY NURSES' OR DOCTORS' OPINIONS.



I PREFER THAT MY NURSE OR DOCTOR AND I SHARE RESPONSIBILITY FOR MAKING THE DECISION THAT IS BEST FOR ME.



I PREFER THAT MY NURSE OR DOCTOR MAKE THE FINAL DECISION AFTER SERIOUSLY CONSIDERING MY OPINION.

I PREFER TO LEAVE THE DECISION TO MY NURSE OR DOCTOR.

Appendix K

Patient Interview Record

ID NO: ________

IF THE PREFERRED AND ACTUAL ROLES FOR EITHER THE DECISION TO HAVE SURGERY OR THE SELECTED POSTOPERATIVE CARE DECISION WERE TWO OR MORE SCALE DIFFERENCES APART, QUESTIONS 1 and 2 WILL BE ASKED.

1. Did you attempt to take any action to achieve your preferred decision making role? _____YES _____NO

IF YES:

(i) What action did you take to attempt achievement of your preferred decision making role? ____________________

____

____

____

____

____

____

____

(ii) Please describe the response you received when you attempted to achieve your preferred decision making role:____

IF NO:

(iii) I would be interested in learning what prevented you from taking action. Could you tell me about it.

2. Did your nurse play a role in helping you or in making it more difficult for you to achieve your preferred decision making role?

____YES ____ NO. IF YES: What role did the nurse play?

IF NO: Was there a reason why the nurse was not involved?____

____

____

IF THE PREFERRED AND ACTUAL ROLES FOR EITHER THE DECISION TO HAVE SURGERY OR THE SELECTED POSTOPERATIVE CARE DECISION WERE ONE OR LESS SCALE DIFFERENCES APART, QUESTIONS 3 AND 4 WILL BE ASKED:

3. To what do you attribute your success in so closely achieving your preferred role in decision making?__________

____

____

____

____

____

____

____

4. Was there anything that the nurse did to help you achieve your preferred decision making role?__________

____

____

____

____

ALL SUBJECTS WILL BE ASKED QUESTION 5

5. While you have been in the hospital, have you ever felt a need for some information about your illness or medical care but did not let your doctor or nurse know about your need?

____ YES ____ NO

IF YES:

(i) I was wondering if you could tell me what prevented you from letting your nurse or doctor know that you needed this information.

(ii) Could you tell me what you wanted more information about but did not ask.

THANK YOU FOR PARTICIPATING IN THIS STUDY.

Appendix L

Development of the Paired Comparisons Questionnaire

Preference for Participation in Postoperative Care Decisions

Postoperative care decisions that are frequently made following cancer surgery were identified by the researcher through discussions with two surgical nurses, two nurse educators, two postoperative cancer patients who had recently been discharged from hospital and a review of the literature. The list of decisions utilized by Ende et al. (1989) and by Beisecker (1988) were examined to determine their applicability to the postoperative cancer patient. No research articles were found about postoperative cancer patients' preference for participation in decision making concerning their postoperative care. The following nine postoperative care decisions were chosen.

1. When the patient should get out of bed for the first time after surgery
2. Which foods should be served to the patient
3. When the patient's dressing should be changed
4. How strong a dose of pain medication the patient should receive
5. When pain medication should be given to the patient
6. If the patient should have a blood transfusion

7. If the patient should receive assistance in dealing with the psychological impact of my illness and surgery
8. What activities the patient should do and avoid doing after being discharged home
9. What day the patient should be discharged from the hospital

Ross's (1974) method of optimal ordering was used to order the 36 pairs which were generated form the total of nine items. When this method is used, maximum spacing of all items is obtained. There is no proof that spacing or ordering effects the choices made by subjects. Achieving maximal distance between all the items makes logical sense even if there is not proof that this makes a difference. The items reworded to reflect the patients perspective. The matrix lay-out consisted of 5 rows and 8 columns. Identical pairs occurred in the odd columns of the fifth row. Ross's rules governing the use of the pairs in the fifth row are: a) Replace the second number in each identical pair with number 1. b) Ignore the pairs occurring in the even columns of the fifth row. When the pairs are presented, their order is determined by beginning at the top of the first column on the left, moving down the column, then progressing to the next column on the right as each column is completed from top to bottom.

The Ross Matrix Format

I	II	III	IV	V	VI	VII	VIII
1-2	2-3	1-3	3-4	1-4	4-5	1-5	5-6
3-n	n-4	4-2	2-5	5-3	3-6	6-4	4-7
4-(n-1)	(n-1)-5	5-n	n-6	6-2	2-7	7-3	3-8
5-(n-2)	(n-2)-6	6-(n-1)	(n-1)-7	7-n	n-8	8-2	2-9
6-(n-3)	(n-3)-7	7-(n-2)	(n-2)-8	8-(n-1)	(n-1)-9	9-n	

The Ross Matrix Applied

I	II	III	IV	V	VI	VII	VIII
1-2	2-3	1-3	3-4	1-4	4-5	1-5	5-6
3-9	9-4	4-2	2-5	5-3	3-6	6-4	4-7
4-8	8-5	5-9	9-6	6-2	2-7	7-3	3-8
5-7	7-6	6-8	8-7	7-9	9-8	8-2	2-9
6-1		7-1		8-1		9-1	

Order of Items

1\. When I should get out of bed for the first time after surgery
2\. Which foods should be served to me

3\. When my dressing should be changed
9\. What day I should be discharged from the hospital

4\. How strong a dose of pain medication I should receive
8\. What activities I should do and avoid doing when I go home

5\. What time my pain medication should be given
7\. If I should receive assistance in dealing with the psychological impact of my illness and surgery

6\. If I should have a blood transfusion
1\. When I should get out of bed for the first time after surgery

2\. Which foods should be served to me
3\. When my dressing should be changed

9\. What day I should be discharged from the hospital
4\. How strong a dose of pain medication I should receive

8\. What activities I should do and avoid doing when I go home
5\. What time my pain medication should be given

7. If I should receive assistance in dealing with the psychological impact of my illness and surgery
6. If I should have a blood transfusion

1. When I should get out of bed for the first time after surgery
3. When my dressing should be changed

4. How strong a dose of pain medication I should receive
2. Which foods should be served to me

5. What time my pain medication should be given
9. What day I should be discharged from the hospital

6. If I should have a blood transfusion
8. What activities I should do and avoid doing when I go home

7. If I should receive assistance in dealing with the psychological impact of my illness and surgery
1. When I should get out of bed for the first time after surgery

3. When my dressing should be changed
4. How strong a dose of pain medication I should receive

2. Which foods should be served to me
5. What time my pain medication should be given

9. What day I should be discharged from the hospital
6. If I should have a blood transfusion

8. What activities I should do and avoid doing when I go home
7. If I should receive assistance in dealing with the psychological impact of my illness and surgery

1. When I should get out of bed for the first time after surgery
4. How strong a dose of pain medication I should receive

5. What time my pain medication should be given
3. When my dressing should be changed

6. If I should have a blood transfusion
2. Which foods should be served to me

7. If I should receive assistance in dealing with the psychological impact of my illness and surgery
9. What day I should be discharged from the hospital

8. What activities I should do and avoid doing when I go home
1. When I should get out of bed for the first time after surgery

4. How strong a dose of pain medication I should receive
5. What time my pain medication should be given

3. When my dressing should be changed
6. If I should have a blood transfusion

2. Which foods should be served to me
7. If I should receive assistance in dealing with the psychological impact of my illness and surgery

9. What day I should be discharged from the hospital
8. What activities I should do and avoid doing when I go home

1. When I should get out of bed for the first time after surgery
5. What time my pain medication should be given

6. If I should have a blood transfusion
4. How strong a dose of pain medication I should receive

7. If I should receive assistance in dealing with the psychological impact of my illness and surgery
3. When my dressing should be changed

8. What activities I should do and avoid doing when I go home
2. Which foods should be served to me

9. What day I should be discharged from the hospital
1. When I should get out of bed for the first time after surgery

5. What time my pain medication should be given
6. If I should have a blood transfusion

4. How strong a dose of pain medication I should receive
7. If I should receive assistance in dealing with the psychological impact of my illness and surgery

3. When my dressing should be changed
8. What activities I should do and avoid doing when I go home

2. Which foods should be served to me
9. What day I should be discharged from the hospital

The numbers beside each item that formed a pair were then replaced by (a) and (b).

Appendix M

Control Preferences Card Sort Procedure

The procedure described for Degner and Russell's (1988) four card sort was adapted for five cards in the following manner. The deck of five cards (A, B, C, D and E) was shuffled by the investigator to put the cards in random order. Two cards were selected and placed on a table in front of the patient (eg., C & E). The patient was asked to indicate: "Which one of these do you like the best for deciding your surgical treatment? Which would you prefer to have in deciding about having your surgery?" The preferred card was placed on top of the other card (eg. E>C). The next card (eg., D) was selected at random from the deck and placed in front of the patient who compared it to his/her previous first choice. If the new card, D, was preferred, it was placed on top of E and C (ie, D>E>C). If it was not, E was turned over, and the patient was asked to compare D with C. If D was preferred, it was placed on top of C (ie, E>D>C); if C was preferred, it was placed on top of D (ie, E>C>D). The process continued until the patient's total preference order on the cards was unfolded. This method of testing was designed to allow patients to unfold their total preference orders without seeing all possible choices at once (Degner & Russell, 1988).

Appendix N

Thurstone Scales of Postoperative Care Decisions Indicating Differences Associated with Gender, Age, Education, Residence, Coexisting Illnesses and Perception of Surgical Outcome.

Definitions of the following abbreviations used in the tables and figures in this appendix are:

OBED: When I should get out of bed for the first time after surgery.
FOOD: Which foods should be served to me.
DRSG: When my dressing should be changed.
DOSA: How strong a dose of pain medication I should receive.
TIMA: What time my pain medication should be given.
BLOD: If I should have a blood transfusion.
PSYC: If I should receive assistance in dealing with the psychological impact of my illness and surgery.
ACTV: What activities I should do and avoid doing when I go home.
DISC: What day I should be discharged from the hospital.

A lower numerical value in the tables indicates a greater preference for input in postoperative care decisions.

Differences of mean z scores and mean proportions between men and women's preferences to participate in postoperative care decisions using Thurstone's Law of Comparative Judgement.

Men (n=21)

Decision	X z score	SD	X Proportion	SD
OBED	0.021	0.445	0.450	0.236
FOOD	-0.166****	0.258	0.381	0.172
DRSG	0.246	0.215	0.540	0.216
DOSA	0.102***	0.473	0.481	0.250
TIMA	-0.028	0.234	0.434	0.187
BLOD	-0.114*	0.293	0.402	0.186
PSYC	-0.054**	0.335	0.423	0.204
ACTV	-0.435	0.367	0.286	0.156
DISC	0.341	0.345	0.571	0.244

Women (n=29)

Decision	X z score	SD	X Proportion	SD
OBED	-0.034	0.520	0.437	0.252
FOOD	0.448****	0.340	0.609	0.250
DRSG	0.295	0.384	0.552	0.272
DOSA	-0.311***	0.380	0.330	0.181
TIMA	-0.029	0.527	0.433	0.256
BLOD	0.083*	0.301	0.475	0.211
PSYC	-0.378**	0.428	0.307	0.188
ACTV	-0.462	0.290	0.272	0.131
DISC	0.345	0.380	0.571	0.249

significant differences between men and women: ****$p<0.001$, ***$p<0.005$, **$p<0.01$, *$p<0.02$

Differences in mean z scores and mean proportions between younger and older patients' preferences to participate in postoperative care decisions using Thurstone's Law of Comparative Judgement.

Less than 65 years (n=27)

Decision	X z score	SD	X Proportion	SD
OBED	0.043	0.419	0.461	0.234
FOOD	0.096	0.309	0.481	0.216
DRSG	0.470***	0.413	0.613	0.263
DOSA	-0.116	0.448	0.403	0.224
TIMA	0.146***	0.448	0.498	0.251
BLOD	-0.147**	0.242	0.387	0.172
PSYC	-0.398*	0.346	0.296	0.159
ACTV	-0.511	0.367	0.259	0.143
DISC	0.404***	0.261	0.597	0.235

65 years old and greater (n=23)

Decision	X z score	SD	X Proportion	SD
OBED	-0.070	0.482	0.420	0.239
FOOD	0.277	0.251	0.551	0.223
DRSG	0.067***	0.400	0.469	0.232
DOSA	-0.164	0.346	0.382	0.193
TIMA	-0.228***	0.321	0.357	0.179
BLOD	0.178**	0.345	0.512	0.232
PSYC	-0.053*	0.285	0.425	0.193
ACTV	-0.381	0.233	0.300	0.129
DISC	0.258***	0.339	0.541	0.236

Significant differences between young and old: ***$p<0.001$, **$p<0.03$, *$p<0.04$

Differences in mean z scores and mean proportions between patients' preferences for participation in postoperative care decisions associated with less than high school graduation education and with high school graduation education or greater using Thurstone's Law of Comparative Judgement.

Less than high school graduation (n=20)

Decision	X z score	SD	X Proportion	SD
OBED	-0.032	0.353	0.433	0.212
FOOD	0.233	0.326	0.533	0.233
DRSG	0.133***	0.381	0.494	0.235
DOSA	-0.067	0.439	0.417	0.225
TIMA	-0.172*	0.288	0.378	0.179
BLOD	0.246****	0.250	0.539	0.220
PSYC	-0.216	0.212	0.361	0.154
ACTV	-0.411	0.369	0.294	0.159
DISC	0.244**	0.352	0.533	0.232

High school graduation or greater (n=30)

Decision	X z score	SD	X Proportion	SD
OBED	0.013	0.532	0.448	0.259
FOOD	0.143	0.270	0.500	0.214
DRSG	0.365***	0.340	0.581	0.247
DOSA	-0.184	0.412	0.378	0.207
TIMA	0.076*	0.530	0.470	0.261
BLOD	-0.164****	0.306	0.381	0.184
PSYC	-0.246	0.364	0.352	0.186
ACTV	-0.480	0.307	0.267	0.132
DISC	0.401**	0.247	0.596	0.234

Significant differences between high and low education:
****p<0.001, ***p<0.005, **p<0.01, *p<0.02

Differences in mean z scores and mean proportions between patients with and without coexisting illnesses in their preferences for participation in postoperative care decisions using Thurstone's Law of Comparative Judgement.

Without coexisting illnesses (n=12)

Decision	X z score	SD	X Proportion	SD
OBED	-0.242**	0.611	0.361	0.257
FOOD	0.070****	0.262	0.472	0.204
DRSG	0.599***	0.516	0.648	0.284
DOSA	-0.286*	0.673	0.352	0.262
TIMA	0.136	0.640	0.491	0.290
BLOD	0.221	0.314	0.528	0.228
PSYC	-0.332**	0.431	0.324	0.192
ACTV	-0.372	0.295	0.306	0.144
DISC	0.173****	0.378	0.509	0.237

With coexisting illnesses (n=38)

Decision	X z score	SD	X Proportion	SD
OBED	0.061**	0.448	0.468	0.244
FOOD	0.211****	0.213	0.526	0.212
DRSG	0.182***	0.318	0.515	0.227
DOSA	-0.096*	0.314	0.406	0.194
TIMA	-0.074	0.370	0.415	0.210
BLOD	-0.067	0.262	0.418	0.187
PSYC	-0.203**	0.242	0.365	0.164
ACTV	-0.471	0.288	0.269	0.128
DISC	0.388****	0.274	0.591	0.236

Significant differences between patients with and without co-existing illnesses: ****$p<0.005$, ***$p<0.015$, **$p<0.03$, *$p<0.05$

Differences in mean z scores and mean proportions in patients' preferences for participation in postoperative care decisions associated their beliefs about the outcome of the surgical procedure using Thurstone's Law of Comparative Judgement.

Cured (n=22)

Decision	X z score	SD	X Proportion	SD
OBED	0.016	0.433	0.449	0.234
FOOD	0.115	0.163	0.490	0.194
DRSG	0.011***	0.347	0.449	0.215
DOSA	-0.036	0.284	0.429	0.194
TIMA	-0.061	0.330	0.419	0.202
BLOD	0.223***	0.254	0.530	0.219
PSYC	-0.133	0.341	0.394	0.196
ACTV	-0.453	0.221	0.273	0.114
DISC	0.238*	0.281	0.535	0.225

Unsure (n=26)

Decision	X z score	SD	X Proportion	SD
OBED	-0.074	0.457	0.419	0.232
FOOD	0.202	0.376	0.521	0.240
DRSG	0.456***	0.371	0.611	0.258
DOSA	-0.188	0.493	0.376	0.230
TIMA	-0.038	0.477	0.432	0.238
BLOD	-0.143***	0.286	0.389	0.182
PSYC	-0.283	0.293	0.338	0.161
ACTV	-0.464	0.460	0.282	0.169
DISC	0.484*	0.425	0.615	0.257

Significant differences between patients who believed they were cured and patients who were unsure about being cured: ***p<0.001, *p<0.03

Differences in mean z scores and mean proportions associated with place of residence in patients' preferences for participation in postoperative care decisions using Thurstone's Law of Comparative Judgement.

Winnipeg (n=33)

Decision	X z score	SD	X Proportion	SD
OBED	-0.009	0.453	0.441	0.238
FOOD	0.148	0.270	0.502	0.214
DRSG	0.139*	0.335	0.498	0.226
DOSA	-0.070**	0.313	0.418	0.198
TIMA	0.048**	0.353	0.461	0.219
BLOD	0.062***	0.263	0.468	0.203
PSYC	-0.298	0.300	0.330	0.163
ACTV	-0.520	0.289	0.253	0.116
DISC	0.418***	0.311	0.599	0.242

Not Winnipeg (n=17)

Decision	X z score	SD	X Proportion	SD
OBED	-0.003	0.441	0.444	0.235
FOOD	0.246	0.303	0.536	0.225
DRSG	0.627*	0.686	0.638	0.290
DOSA	-0.273**	0.592	0.346	0.236
TIMA	-0.256**	0.723	0.381	0.233
BLOD	-0.120***	0.318	0.399	0.192
PSYC	-0.101	0.226	0.405	0.175
ACTV	-0.326	0.441	0.327	0.195
DISC	0.189***	0.360	0.516	0.237

Significant differences between patients residing in Winnipeg and patients not residing in Winnipeg :
***p<0.001, **p<0.005,, *p<0.05

Appendix O

Thurstone Scaling of Decision Making Roles Indicating Differences According to Gender, Age, Education, Residence, and Perception of Surgical Outcome

In the tables listed below, lower values of z scores indicate a greater preference. The definitions of Roles ABCDE are as follows:

A: "I prefer to make the final selection about which treatment I will receive."

B: "I prefer to make the final selection of my treatment after seriously considering my Doctor's opinion.'

C: "I prefer that my Doctor and I share responsibility for deciding which treatment is best for me."

D: "I prefer that my Doctor makes the final decision about which treatment will be used, but seriously considers my opinion."

E: "I prefer to leave all decisions regarding my treatment to my Doctor."

<u>Differences in mean z scores, associated with gender, in patient's preferences for participation in surgical treatment decision making using Thurstone's Law of Comparative Judgement.</u>

Role	Men (n=21) Mean z score	SD	Women (n=29) Mean z score	SD
A	0.319	0.187	0.347	0.292
B	0.230	0.458	0.197	0.297
C	-0.082	0.484	-0.078	0.478
D	-0.225	0.364	-0.291	0.331
E***	-0.242	0.135	-0.175	0.116

*** $p<0.005$

Differences in mean z scores associated with age, in patients' preferences for participation in surgical treatment decision making using Thurstone's Law of Comparative Judgement.

Role	<65 Years (n=23)		>=65 Years (n=27)	
	Mean z score	SD	Mean z score	SD
A****	0.271	0.282	0.414	0.275
B****	0.098	0.339	0.360	0.477
C	-0.075	0.405	-0.078	0.623
D***	-0.330	0.281	-0.181	0.440
E****	0.037	0.021	-0.515	0.303

**** $p<0.001$, *** $p<0.005$

Differences in mean z scores of surgical treatment decision roles associated with place of residence.

Role	Winnipeg (n=33)		Not Winnipeg (n=17)	
	Mean z score	SD	Mean z score	SD
A	0.403	0.296	0.214	0.256
B	0.256	0.374	0.130	0.426
C	-0.125	0.555	0.009	0.424
D	-0.189	0.359	-0.412	0.351
E****	-0.345	0.202	0.059	0.033

**** $p<0.001$

Differences in mean z scores associated with level of formal education, in patients' preferences for participation in surgical treatment decision roles.

	<High School Grad(n=20)		>=High School Grad(n=30)	
Role	Mean z score	SD	Mean z score	SD
A****	0.452	0.280	0.260	0.262
B****	0.331	0.510	0.140	0.326
C**	-0.030	0.639	-0.105	0.384
D****	-0.180	0.529	-0.313	0.252
E****	-0.573	0.328	0.017	0.037

**** $p<0.001$, ** $p<0.03$

Differences in mean z scores, associated with whether or not patients had coexisting illness, in their preferences of surgical treatment decision roles using Thurstone's Law of Comparative Judgement.

	With Coexisting Illnesses (n=38)		Without Coexisting Illnesses (n=12)	
Role	Mean z score	SD	Mean z score	SD
A*	0.372	0.251	0.216	0.303
B**	0.297	0.413	-0.042	0.319
C	-0.093	0.563	-0.042	0.319
D	-0.251	0.401	-0.301	0.193
E****	-0.326	0.189	0.168	0.094

**** $p<0.001$, ** $p<.01$, * $<p<0.05$

Differences in mean z scores associated with patients' perception of surgical outcome, in the preferences for surgical treatment decision roles, using Thurstone's Law of Comparative Judgement.

Role	Cured (n=22) Mean z score	Cured (n=22) SD	Not Sure (n=26) Mean z score	Not Sure (n=26) SD
A****	0.492	0.327	0.243	0.309
B	0.079	0.592	0.328	0.327
C	-0.050	0.433	-0.108	0.565
D**	-0.116	0.372	-0.327	0.348
E****	-0.405	0.233	-0.136	0.087

**** p<0.001, ** p<0.015

Appendix P

Thurstone Scaling of Postoperative Care Decisions According to Decision Making Role Categories

Definitions of the following abbreviations used in the tables and figures in this appendix are:

OBED: When I should get out of bed for the first time after surgery.
FOOD: Which foods should be served to me.
DRSG: When my dressing should be changed.
DOSA: How strong a dose of pain medication I should receive.
TIMA: What time my pain medication should be given.
BLOD: If I should have a blood transfusion.
PSYC: If I should receive assistance in dealing with the psychological impact of my illness and surgery.
ACTV: What activities I should do and avoid doing when I go home.
DISC: What day I should be discharged from the hospital.

A lower numerical value in the tables indicates a greater preference for input in postoperative care decisions.

Thurstone scaling of preferred postoperative care decisions in patients who preferred passive or active/collaborative surgical treatment decision role categories.

Passive (n=29).

Decision	X z score	SD	X Proportion	SD
OBED	-0.051	0.494	0.425	0.241
FOOD	0.127	0.200	0.494	0.200
DRSG	0.109**	0.314	0.487	0.219
DOSA	-0.057*	0.347	0.421	0.207
TIMA	-0.089	0.313	0.410	0.195
BLOD	0.260***	0.353	0.540	0.236
PSYC	-0.279	0.362	0.341	0.180
ACTV	-0.479	0.241	0.264	0.113
DISC	0.378	0.305	0.586	0.241

Active/collaborative (n=21).

Decision	X z score	SD	X Proportion	SD
OBED	0.057	0.408	0.466	0.233
FOOD	0.253	0.301	0.540	0.227
DRSG	0.524**	0.434	0.630	0.269
DOSA	-0.253*	0.492	0.354	0.221
TIMA	0.045	0.539	0.466	0.259
BLOD	-0.347***	0.246	0.312	0.139
PSYC	-0.183	0.317	0.376	0.184
ACTV	-0.416	0.477	0.296	0.192
DISC	0.293	0.387	0.550	0.243

Significant differences between patients preferring passive role categories and patients preferring active/collaborative role categories: *** $p<0.001$, ** $p<0.005$, * $p<0.05$

Thurstone scaling of preferred postoperative care decisions in patients who assumed passive or active/collaborative postoperative care decision role categories.

Passive (n=14).

Decision	X z score	SD	X Proportion	SD
OBED	0.120*	0.620	0.476	0.270
FOOD	0.041	0.254	0.460	0.199
DRSG	0.284	0.478	0.548	0.267
DOSA	-0.166	0.365	0.381	0.196
TIMA	-0.254	0.320	0.349	0.173
BLOD	0.166***	0.286	0.508	0.219
PSYC	0.061***	0.372	0.468	0.226
ACTV	-0.621	0.543	0.238	0.164
DISC	0.266	0.495	0.532	0.248

Active/collaborative (n=36).

Decision	X z score	SD	X Proportion	SD
OBED	-0.043*	0.461	0.429	0.237
FOOD	0.231	0.330	0.534	0.216
DRSG	0.268	0.315	0.546	0.234
DOSA	-0.120	0.382	0.398	0.209
TIMA	0.060	0.448	0.466	0.243
BLOD	-0.063***	0.267	0.420	0.188
PSYC	-0.347***	0.273	0.312	0.149
ACTV	-0.401	0.277	0.293	0.139
DISC	0.372	0.235	0.586	0.231

Significant differences between patients assuming passive role categories and patients assuming active/collaborative role categories: ***$p<0.001$, *$p<0.03$

Thurstone scaling of preferred postoperative care decisions of patients in client who assumed passive or active/collaborative surgical treatment decision making roles.

Passive (n=36).

Decisions	X z score	SD	X Proportion	SD
OBED	-0.005	0.494	0.441	0.247
FOOD	0.136	0.251	0.497	0.209
DRSG	0.226	0.311	0.531	0.230
DOSA	-0.095*	0.361	0.407	0.206
TIMA	-0.038	0.350	0.429	0.209
BLOD	0.056***	0.257	0.466	0.201
PSYC	-0.241	0.274	0.352	0.165
ACTV	-0.490	0.287	0.262	0.124
DISC	0.376	0.266	0.586	0.233

Active/collaborative (n=14).

Decisions	X z score	SD	X Proportion	SD
OBED	-0.002	0.386	0.444	0.222
FOOD	0.297	0.314	0.556	0.234
DRSG	0.408	0.503	0.587	0.276
DOSA	-0.245*	0.480	0.357	0.214
TIMA	-0.005	0.435	0.444	0.234
BLOD	-0.143***	0.258	0.389	0.175
PSYC	-0.212	0.373	0.365	0.194
ACTV	-0.351	0.405	0.317	0.179
DISC	0.232	0.302	0.532	0.226

Significant differences between patients assuming passive role categories and patients assuming active/collaborative role categories: ***$p<0.001$, *$p<0.03$

Thurstone scaling of postoperative care decisions of patients assuming passive or active/collaborative postoperative care decision role categories.

Passive (n=16)

Decision	X z score	SD	X Proportion	SD
OBED	-0.236***	0.455	0.361	0.207
FOOD	0.089***	0.279	0.479	0.210
DRSG	0.289	0.266	0.556	0.228
DOSA	-0.182	0.435	0.382	0.206
TIMA	0.131	0.492	0.486	0.250
BLOD	-0.088	0.179	0.410	0.169
PSYC	-0.110	0.285	0.403	0.185
ACTV	-0.316	0.328	0.326	0.165
DISC	0.332	0.421	0.563	0.250

Active/collaborative (n=14).

Decision	X z score	SD	X Proportion	SD
OBED	0.197***	0.463	0.516	0.257
FOOD	0.438***	0.385	0.603	0.255
DRSG	0.277	0.392	0.548	0.250
DOSA	-0.169	0.486	0.381	0.226
TIMA	-0.131	0.466	0.397	0.229
BLOD	-0.124	0.278	0.397	0.182
PSYC	-0.394	0.405	0.302	0.174
ACTV	-0.498	0.345	0.262	0.143
DISC	0.314	0.288	0.563	0.233

Significant differences between patients assuming passive role categories and patients assuming active/collaborative role categories : ***p<0.001