FIRST TIME CHEMOTHERAPY RECIPIENTS' KNOWLEDGE FOLLOWING CHEMOTHERAPY EDUCATION

A THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF MASTER OF SCIENCE

IN THE GRADUATE SCHOOL OF

TEXAS WOMAN'S UNIVERSITY

COLLEGE OF HEALTH SCIENCES

BY

PATRICIA D. VANMAANEN, B.S.N., R.N., OCN

DENTON, TEXAS

DECEMBER 1996

TEXAS WOMAN'S UNIVERSITY

October 24, 1996

To the Associate Vice President for Research and Dean of the Graduate School:

I am submitting herewith a thesis written by Patricia VanMaanen entitled "First Time Chemotherapy Recipients' Knowledge Following Chemotherapy Education." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Health Studies.

Susan Ward

Major Professor

We have read this thesis and recommend its acceptance:

Judith A Bahr

Eva Doyle

William B. Cissell

Chair, Department of Health Studies

Accepted:

Leslie M Thompson

Associate Vice President for Research and Dean of the Graduate School

DEDICATION

I dedicate this to all the cancer patients and the oncology nurses I have had the great pleasure to work with who have made my life more fulfilling and my career more rewarding. I only hope this study will bring further awareness to those of us in oncology nursing and challenge us to strive even harder for excellent care for our courageous patients.

ACKNOWLEDGEMENTS

I wish to thank my chairperson, Dr. Susan Ward, for her guidance, support, and encouragement throughout this project. A special thank you for her willingness to help with data analysis. Thank you to my committee members, Dr. Eva Doyle and Dr. Judy Baker, for their wisdom, their support when IRB approval looked bleak, and their knowledge of APA and Graduate School formatting, which would have gotten the best of me without their assistance.

A special thank you and deep appreciation goes to Barb Richardson, RN, BSN, OCN, Director of Research Nursing at Texas Oncology, P. A. She was instrumental in implementing this first nursing research study at her institution. She and Dr. John Nemunaitis, Director Clinical Research at Texas Oncology, P. A., stood behind the study when others questioned it relevance, and for this I am forever indebted.

A special thanks is extended to all the wonderful nurses in the outpatient clinics that gave of their time and were so committed to

the study. Patient accrual would not have been possible without their dedication and assistance with the study. I only hope the findings of the study will enhance their practice as it has mine.

I would like to thank all my friends for their support and understanding during this endeavor. A special thanks to my buddies in Ann Arbor that would visit or call to provide a much needed school break from time to time.

Last but certainly not least, a heart felt thank you to my beloved Marcel for his love, support, and understanding which kept me sane when I felt otherwise.

ABSTRACT

COMPLETED RESEARCH IN HEALTH SCIENCES
Texas Woman's University, Denton, Texas

VanMaanen, P. D. First Time Chemotherapy Recipients' Knowledge Following Chemotherapy Education. M.S. in Health Studies, 1996, 135 pp. (S. Ward).

The purpose of the study was to determine the difference between the chemotherapy knowledge score obtained following the chemotherapy education and prior to the third cycle of chemotherapy for first time chemotherapy recipients. Data were collected on 32 participants and nine variables, which included age, gender, education level, cancer diagnosis, purpose of treatment, drug and side effect knowledge, frequency of phone calls to the doctor, and the usefulness of educational information. A comparison of the two chemotherapy knowledge scores was determined using a t-test, which indicated no statistical difference in the scores. Utilizing Pearson r, no correlation was noted between the frequency of phone calls to the doctor and the participant's knowledge score. Nearly half of the participants were not aware of their treatment's purpose.

Most of the patients could recall the distressing side effects such as nausea, however, less than 30% could recall the side effects, infection and bleeding.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1

INTRODUCTION

Technological advances and cost containment in recent years have lead to shortened hospital stays, changes in treatment modalities, and increased services offered in alternative settings (Dodd, 1984; Dodd & Mood, 1981). Chemotherapy administration has moved from the hospital to the outpatient setting as a direct result of this. Consequently, the patient is given the increased responsibility for managing self-care which increases the need for knowledge that will empower the patient to manage self-care deficits more effectively. If patients are not adequately prepared to manage the side effects of chemotherapy, the resulting morbidity may necessitate dosage reductions, cycle delays, and changes in the choice of chemotherapy agents used, all of which adversely affect the likelihood for cure or prolonged survival (Dodd & Dibble, 1993).

Most recent research studies conducted in this area have focused on self care, self-care behaviors, and the prediction of who

will perform and when will they perform self care behaviors. These studies assume that the patient receiving chemotherapy has been given education about the treatment regime and understands the information received (Dodd, 1988; Dodd, 1984; Dodd 1982; Dodd & Dibble, 1993; Dodd & Musci, 1990; Hanucharurnkul, 1989; and Nail et al., 1991). These researchers are looking beyond knowledge retention to patient activity following patient education programs. Only two studies (Dodd & Mood, 1981; Muss et al., 1979) were found that addressed knowledge retention following chemotherapy education and both studies have shown that patients undergoing chemotherapy demonstrate inadequate knowledge concerning their disease and their therapy. It seems premature to assume that knowledge has been obtained and is understood, without first documenting that the knowledge is present and retained for anticipated future use.

Treatment protocols, outpatient services, and cancer survival have drastically changed since Dodd and Mood (1981) and Muss et al. (1979) conducted their studies. Current studies are needed to evaluate the present programs used in outpatient settings as well as

knowledge retained by patients over time. These studies should demonstrate that chemotherapy recipients are knowledgeable of their treatment regime and that they can intervene appropriately and timely when side effect signs and symptoms occur.

Purpose of the Study

The purpose of the study was to determine the difference between the chemotherapy knowledge score obtained immediately following the chemotherapy education and prior to the third cycle of chemotherapy for Texas area first time chemotherapy recipients.

Research Questions

For the purpose of this study, the research questions were as follows:

1. How many first time chemotherapy recipients report side effects that are not related to their chemotherapy treatment?

2. How many first time chemotherapy recipients report they are able to read and understand the educational information they received about their chemotherapy treatment?

3. How useful do first time chemotherapy recipients find the educational information they received about their chemotherapy treatment?

4. How frequently do first time chemotherapy recipients contact their oncologist regarding side effect management issues during their chemotherapy treatment?

Hypotheses

For the purpose of this study, the hypotheses were as follows:

1. There is no statistically significant difference between the chemotherapy knowledge score of the Texas area first time chemotherapy recipients taken immediately following the chemotherapy education and the score taken prior to the third cycle of chemotherapy.

2. There is no relationship between the number of phone calls made by the first time chemotherapy recipients to their oncologist and the first time chemotherapy recipient's chemotherapy knowledge score taken prior to the third cycle of chemotherapy.

Definition of Terms

For this study the following terms will be defined as follows:

1. First Time Chemotherapy Recipient. An individual receiving chemotherapy for treatment of cancer who has never received chemotherapy in the past.

2. Chemotherapy. A medication classified as an anti-neoplastic agent used for the treatment of cancer.

3. Texas Area. The geographic location involving the state of Texas where first time chemotherapy recipients will be receiving their chemotherapy treatments.

4. Infusion Center. A room or designated area within an outpatient oncology office that is used to administer chemotherapy and is staffed by a nurse designated to administer the chemotherapy treatments.

5. Chemotherapy Education. Standard verbal and written information provided by the infusion center nurse to individuals who will be receiving chemotherapy.

6. Chemotherapy Knowledge Questionnaire. An instrument used to determine the chemotherapy knowledge of

individuals who have received chemotherapy educational information.

Limitations

The study included the following limitations:

1. First time chemotherapy recipient's prior knowledge about chemotherapy is unknown.

2. First time chemotherapy recipient's level of anxiety, state of grief over diagnosis, and health status are unknown.

Delimitations

The study included the following delimitations:

1. The participants were first time recipients of chemotherapy with a diagnosis of cancer.

2. The participants were those being treated in the state of Texas only.

3. A short time interval was used to test first time recipients of chemotherapy utilizing the same instrument.

4. Each participant was 18 years or older, was physically able to participate, was mentally competent (could complete the instrument), was able to understand the English language, and had a life expectancy of six months or greater.

Assumptions

The assumptions of the study included the following:

1. The infusion center nurses would provide each first time chemotherapy recipient the same educational information.

2. Knowledge is complex, but can be measured.

3. The first time chemotherapy recipients would be willing to participate in the study.

4. The first time chemotherapy recipients would answer the questionnaire to the best of their abilities.

Significance of the Study

Education programs delivered prior to initiation of chemotherapy treatment have gained wide acceptance and implementation as treatment protocols move to outpatient settings.

Many outpatient oncology clinics located in Texas that provide comprehensive chemotherapy services for cancer patients have initiated a similar education program. However, like many programs, the standardized information is presented in one session prior to the first administration of chemotherapy. No evaluation of the education session or the knowledge retained by the chemotherapy recipient is performed.

Also, scant data confirm the effectiveness and value of the education programs. Studies to evaluate the education programs are needed to ensure that the patients gain the knowledge to respond timely and appropriately to side effects that occur as a result of chemotherapy. Studies by Dodd and Mood (1981), Dodd (1988), and Muss et al. (1979) have shown that patients undergoing chemotherapy demonstrate inadequate knowledge concerning their disease and their therapy.

Patient's knowledge of the names and potential side effects of their chemotherapy drugs is a major health care issue, especially when after hours care is used (Dodd & Mood, 1981). The inability of patients to identify their treatment regime to on-call, covering, or

emergency room physicians could result in serious errors. Chemotherapy recipients may delay seeking assistance for symptoms of side effects if they lack knowledge regarding their treatment protocol. However, when cancer patients who were receiving chemotherapy were provided information specific to their situation they demonstrated enhanced self-care activities (Dodd, 1988).

This can only be assured when nurses, the principal healthcare professional responsible for delivering the education programs, provide patient education that not only provides information but also provides patients with support, control, and knowledge to empower them to manage their treatments more effectively (Richardson, 1991). Also, attention must be paid to variables that affect learning such as physical condition, stage of life, information preferences, and emotional responses to disease (Fredette, 1990).

Once research demonstrates that chemotherapy recipients have received information about their treatment regime and their disease further studies can be conducted to determine how they use this information. Patients receiving chemotherapy must be aware of the range of side effects they are likely to experience and the

appropriate self care skills to practice in order to alleviate the symptoms of the side effects (Nail et al., 1991). Only then prediction of self care performance can be made.

CHAPTER 2

REVIEW OF THE LITERATURE

This literature review includes an overview of the published literature from 1979 to 1995 that addresses education of patients receiving chemotherapy. The first section of this chapter will present information about the need of education for those receiving chemotherapy and how this information has been delivered over time. The next section discusses two previous studies that provided the model for the study presented in this paper. The final section presents a synopsis of studies conducted primarily in the 1980's that assessed chemotherapy patients' self-care behaviors while receiving chemotherapy. A summary concludes the chapter.

Patient Education For Those Receiving Chemotherapy

Chemotherapy administration has moved from the hospital to the outpatient setting as a direct result of health care reform and cost containment issues (Dodd & Dibble, 1993). Consequently, the

patient is given the increased responsibility for managing self-care which increases the need for knowledge that will empower the patient to manage self-care deficits more effectively. If patients are not adequately prepared to manage the side effects of chemotherapy, the resulting morbidity may necessitate dosage reductions, cycle delays, and changes in the choice of chemotherapy agents used, all of which adversely affect the likelihood for cure or prolonged survival (Dodd & Dibble, 1993). A systematic educational approach to prepare the patient must be developed and utilized by healthcare individuals involved in the treatment of cancer patients (Teich & Raia, 1984).

Informing patients of the benefits and risks of cancer treatment has gained wide interest and acceptance (Muss et al., 1979). Muss et al. (1979) adds that because most of these patients experience some drug toxicity and because many of them occasionally seek emergency care from physicians who have no access to their records, this aspect of patient education is critically important. A patient's lack of knowledge regarding potentially lethal side effects could result in delay in health seeking behaviors in the

event of the appearance of symptoms of these side effects (Dodd & Mood, 1981).

Early research studies discuss the development of standardized teaching plans as a means to ensure proper education of chemotherapy patients. Myers, Davidson, Hutt, and Chatham (1987) determined that quality nursing care involved teaching the patient how to manage the effects of cancer and its treatment. Information sheets were developed as a reference for patients and seen as important in the delivery of patient education (Myers et al., 1987). Furthermore, standardized teaching tools ensure that patients receive all the necessary information. A successful experience depends on patient involvement in the education process. This is accomplished by clearly identifying learning objectives that list the patient self-care responsibilities (Reville & Almadrones, 1989).

Teich and Raia (1984) used a structured education program to prepare patients to receive continuous infusion chemotherapy at home. The nurses used one-on-one instruction, written information for reference, video tapes, and demonstration with return demonstration to educate patients and their families to assume self-

care of the chemotherapy treatment. The authors observed increased independence and mobility when the patients participate in self-care. Hiromoto and Dungan (1991) used a contract learning protocol to reinforce management of self care deficits which was found to increase self care activities of patients undergoing chemotherapy treatments.

For any patient education to be effective, attention must be paid to variables that affect learning such as physical condition, stage of life, information preferences, and emotional responses to disease (Fredette, 1990). When patients are diagnosed with cancer, they undergo an emotional experience that can cause stress according to Dougherty and Stuttaford (1993). Failure to attend to the emotional response to the disease can prevent self-care learning (Fredette, 1990). However, when cancer patients who were receiving chemotherapy were provided information specific to their situation, they demonstrated enhanced self-care activities (Dodd, 1988).

As the demand for chemotherapy treatments increase in outpatient settings due to reimbursement issues, patients who perform self-care behavior provide a key to patient safety during

chemotherapy treatments. This can only be assured when nurses provide patient education that not only provides information but also provides patients with support, control, and knowledge to empower them to manage their treatments more effectively (Richardson, 1991).

Studies of Chemotherapy Patients' Knowledge Following Education

To date there have been two previous studies that this research study closely resembles. The first study was conducted by Muss et al. (1979) and the purpose was to evaluate patient's knowledge of and perceptions of the purpose, risks, and benefits of chemotherapy. Dodd and Mood (1981) conducted the second study to determine the knowledge cancer patients receiving chemotherapy have about their therapy and to determine the role of the nurse in reviewing chemotherapy information with cancer patients.

The Muss et al. (1979) study consisted of 100 breast cancer women under chemotherapy treatment, 35 adjuvant cases and 65 advanced cases, and being seen in an oncology clinic during a six week data collection period. After receiving information about their

diagnosis and treatment plan, the patients signed an informed consent form attesting their complete understanding of the purpose and the possible side effects of their treatment. Next, the patients were given a questionnaire to complete. This questionnaire asked the participants to recall the chemotherapy drugs currently being given to them, the possible side effects and complications they had been told might result from the receipt of these drugs, and the purpose of their chemotherapy treatment.

The questionnaire was read to each participant or completed by the participant in the presence of one of three researchers. The questionnaire was administered once, 0 to 24 months after the start of their chemotherapy treatment. The participants were asked to identify from a list of 16 side effects, the side effects that they had experienced as well as those they were told would likely occur. This was done to determine if experiencing side effects introduced any bias into the correct or incorrect identification of possible side effects (Muss et al., 1979). The participants' medical records were reviewed to verify their answers to the questionnaire.

The statistical analysis for this study consisted of using a chi-square test and a one-way analysis of variance with a probability level set at .05. Descriptive data were also utilized. The researchers found that over 40% of participants could not correctly identify their chemotherapy drug names. Seventeen percent of adjuvant and 29% of advanced patients were unable to identify any of their drugs. Only six participants correctly identified the possible side effects that could occur with their chemotherapy treatment. An average of 3.44 errors in identifying their side effects were made. While most patients recognized distressing side effects such as nausea and hair loss, less that 50% were aware of the potentially lethal complications of infection and bleeding. Overall, poor recall of possible side effects was observed.

Only 29% correctly responded that cure was the purpose of their chemotherapy treatment while 55% correctly stated that control was the purpose of their treatment. The explanation of the treatment purpose was not well understood or remembered (Muss, et al., 1979).

Muss et al. (1979) also examined each side effect in relation to the participants' self-reports as to whether they had actually experienced the side effect. The results showed that the report of experiencing the side effect has minimal relationship with the participant's recall of the side effect as a potential consequence of receiving the chemotherapy agents.

Muss et al. (1979) interviewed chemotherapy patients in various stages of treatment. During their analysis, Muss et al. (1979) found no significant relationship between the length of time from onset of chemotherapy to the study interview and the knowledge of chemotherapy agents taken, the knowledge of the purposes of the chemotherapy treatment, or the errors in identification of potential side effects.

Muss et al. (1979) concluded that patients undergoing chemotherapy treatment demonstrate inadequate knowledge concerning their disease and their therapy. The authors speculated it is possible that for some patients, this lack of knowledge is a component of a protective denial mechanism and that more attempts at education will be met with depression, frustration, or lack of

further knowledge increment. However, when given the chance, patients have shown that they can learn the names of their chemotherapy drugs, suggesting that patient education can lead to better prepared patients who can participate in their therapy (Muss et al., 1979).

The Dodd and Mood (1981) study consisted of two parts. The first part was a descriptive study to determine how much information was retained from the informed consent procedure by adult oncology patients receiving chemotherapy for a variety of malignancies. In the second part of the study, participants were randomly assigned to receive an information visit by a nurse after the physician had obtained informed consent.

The purpose of the first part of the study was to determine the degree of retention of the information given during the informed consent procedure by adult oncology patients receiving chemotherapy for a variety of malignancies. This part of the study was not limited to breast cancer as was the Muss et al. (1979) study but otherwise was a duplication of that study.

Selection criteria for this study required that participants be 18 years or older, mentally competent, physically able to participate, able to understand the English language, registered in one of the approved chemotherapy protocols, and receiving chemotherapy which began within the last calendar year. The selection criteria was primarily a requirement for completing the study questionnaire. Thirty participants, 12 males and 18 females, were included in this study. Diagnoses represented included gastrointestinal (13 participants), breast (7), head and neck (5), lung (3), and ovarian cancer (2). Each participant received the standard education provided to individuals consenting to phase I and phase II clinical trials of experimental chemotherapeutic agents.

The study was conducted in a 909-bed research hospital and in an adjoining oncology office. Participants completed a modified version of the Muss et al. (1979) questionnaire. In addition to providing the purpose of their treatment, the names of their chemotherapy agents, and the potential side effects that could occur due to the chemotherapy agents, participants were asked who provided their chemotherapy education and what effect did the

information have on them. The modified questionnaire was reviewed for content validity.

The study found that 70% of the participants could not recognize any of their chemotherapy drugs and less that one-third of the side effects were identified by the participants in the study. On average 3.56 potential side effects of 11.86 possible side effects were correctly identified. They also identified 2.13 side effects incorrectly. Only 10 (33%) of the 30 participants identified infection as a potential side effect and none (0%) of the participants identified bleeding as a potential side effect.

Dodd and Mood (1981) determined from this part of the study that patients receiving chemotherapy for the treatment of cancer recalled little of the information given to them in the course of obtaining their consent to participate. They were typically unable to recognize the names of the drugs they were receiving or the potential side effects that had been identified for them. Awareness of a potential side effect did not appear to increase the likelihood of its being experienced and symptoms experienced were frequently incorrectly attributed to the chemotherapy agents. Patients were

generally aware of the purpose of the chemotherapy if it was for cure, however, this was less true for those receiving chemotherapy for the purpose of disease control.

The purpose of the second part of this study was to determine if randomly assigned participants, half of whom received an information visit by a nurse following informed consent, showed greater accuracy of recall of information three to four weeks later than the control participants who received a placebo (noninformative) visit by a nurse. Twenty-four participants participated in this study and were selected using similar criteria as the first part of the study. These participants were randomly assigned to either the experimental or control group.

The nurse visited the participants within 48 to 72 hours after informed consent was obtained. The 12 participants in the experimental group received a review of the information given during the informed consent procedure regarding the chemotherapuetic agent(s) and its (their) potential side effects. Each individual in this group also received an index card with this information which they could keep for future review. The 12

patients in the control group received diseased-related information during their visit by a nurse. Both types of visits lasted 20 minutes. Three to four weeks after the nurse's visit, the participants answered the same questionnaire used in the first part of this study.

The results of this part of the study showed that the experimental group recalled significantly more of their chemotherapy names and potential side effects than did the control group. The accuracy of recognition of the potentially lethal side effects (bleeding and infection) was the most pronounced between the two groups with an accuracy rate of 71% for the experimental group and 21% for the control group.

Dodd and Mood (1981) concluded that the first part of this study demonstrated similar findings as did Muss et al.'s (1979) study. Muss et al. (1979) found that 46% of their sample was unable to identify any of their drugs while 70% of this sample was unable to recognize any of the names of their chemotherapeutic agents. Also, more of the participants in the Dodd & Mood (1981) study were unable to recognize potential side effect which might occur as a

result of the chemotherapy they were receiving than the participants in the Muss et al. (1979) study.

The findings of part two of this study indicated to the authors that patients to whom chemotherapy was explained by personnel in addition to the physician were more able to identify critical information about their therapy as compared to those patients for whom the physician was the sole informant. The experimental group was able to recognize significantly more chemotherapy names, potential side effects, and purpose of treatment. The control group performed similarly to the group in part one of this study, indicating that the disease-related information did little to influence the participants' responses to the questionnaire. It also shows that loss of information occurs quickly considering that this group was studied only three to four weeks following their entry into the chemotherapy regime.

The authors conclude that patients undergoing chemotherapy have inadequate knowledge concerning their disease and their therapy. The role of the nurse was demonstrated in the second part

of the study and indicates that nurses can and do play a crucial role in patient education.

Self-Care Behaviors of Chemotherapy Patients

Several studies followed the Muss et al. (1979) and the Dodd and Mood (1981) studies. These studies look beyond knowledge retention and address performance of self-care behaviors as a result of side effects experienced from receiving chemotherapy agents. These studies assume patient education has been received and knowledge is present in order for performance of self-care activities to occur. Self-care activities rely heavily on knowledge and skills the patient already possess but little is known regarding how patients manage illness and self-care deficits (Dodd, 1984). However, it is thought that four stages of illness control is utilized: perception and interpretation, planning, performing specific actions, and evaluating the impact of these actions (Dodd, 1982).

Hanucharurnkul (1989) and Dodd and Dibble (1993) conducted studies that addressed self-care behavior prediction. One hundred-twelve cervical and head and neck patients undergoing radiation

therapy were asked to complete a questionnaire. The study determined that adequate social support and socioeconomic status were significant predictors of self-care behavior performance while age, marital status, and living arrangements were not (Hanucharurnkul, 1989). Hanucharurnkul (1989) also found that stage and site of cancer seemed to be a predictor of self-care indirectly through social support. Those with support were more likely to engage in health promoting behavior and less likely to develop health concerns.

Dodd and Dibble (1993) interviewed 127 first time chemotherapy recipients before their first cycle of chemotherapy, at their nadir point, and at each of the next three chemotherapy cycles to determine a profile of patients who perform self-care behaviors. Demographic variables, performance status, affective state, social support, the ability to manage a situation, self-care ability, and prior health promoting activities were found to be predictors of self-care performance. Specifically, those with decreased performance status, increased anxiety, minimal social support, or more education

performed more self-care activities. Also, it was noted that experiencing side effects served as a stimulus to perform self-care.

To provide further understanding of self-care performance studies by Dodd (1982; 1984) randomized cancer patients into groups to determine their self-care behaviors. One group received drug information only, one group received information on side effect management techniques (SEMT), another group received combined drug and SEMT information, and the last group was a control group. Those who received drug information had a higher chemotherapy knowledge score though the score was comparable to retention scores noted in Dodd and Mood (1981) and Muss et al. (1979) studies. Patients who received SEMT performed more self-care behaviors (Dodd, 1982; 1984). Dodd (1983) found that patients who were informed performed self-care behaviors sooner and before side effects became persistent and severe. These studies conclude that self-care behaviors can be learned (Dodd, 1983; 1984; 1988).

Nail et al. (1991), Dodd (1988), and Musci and Dodd (1990) conducted studies that requested cancer patients receiving chemotherapy to keep a self-care behavior log where each side effect

would be recorded. The severity and intensity of the side effect as well as the self-care behavior performed and it's effectiveness was recorded in the log over a range of six weeks to six months. The more familiar side effects were found to receive more self-care behaviors performed (Dodd, Dibble, & Thomas, 1993), suggesting that performance of side effect management is limited only by the lack of knowledge. Sitzia, Hughes, and Sobrido (1995) and Nail et al. (1991) documented that fatigue was the most frequently reported side effect while Dodd (1982; 1988) reported nausea and vomiting as the most frequently reported side effects. The difference may be due in part to the increased effectiveness of antiemetics introduced to the market in recent years.

Summary

Education programs delivered prior to initiation of chemotherapy treatment have gained wide acceptance and implementation as treatment protocols move to outpatient settings. However, scant data confirm the effectiveness and value of the programs. Studies to evaluate the education programs are needed to

ensure that the patients gain the knowledge to respond timely and appropriately to side effects that occur as a result of chemotherapy. Studies by Dodd and Mood (1981) and Muss et al. (1979) have shown that patients undergoing chemotherapy demonstrate inadequate knowledge concerning their disease and their therapy. These studies were conducted when treatments were given more frequently in hospital settings and were conducted with treatment regimes that are no longer relevant to current therapy modalities. Also, neither study tested knowledge over time. Studies are needed to evaluate the current programs used in outpatient settings as well as knowledge retained by patients over time. Once the knowledge level of chemotherapy recipients is known, the activities initiated as a result of the knowledge can be evaluated in further detail to determine what prompts chemotherapy patients to use the knowledge to perform self-care measures.

CHAPTER 3

METHODOLOGY

The methodology of this descriptive study is discussed in relationship to the following: (a) setting, (b) population and sample, (c) procedures to collect the data, (d) instruments utilized to collect the data, and (e) treatment of the data. In addition, the protection of human subjects is also discussed.

Setting

The study was conducted within six outpatient cancer centers located in Texas and managed by Texas Oncology, P. A. Each cancer center contained an infusion center used to administer chemotherapy to individuals requiring such treatment for cancer. Four clinics were located in a large metropolitan area in north Texas. The remaining two clinics were located in smaller metropolitan areas, one in southwest Texas and the other in southeast Texas.

Population and Sample

The target population of this study was first time recipients of chemotherapy with a diagnosis of cancer. All participants received their treatment in Texas. Each participant was 18 years or older, physically able to participate, mentally competent (able to complete the instrument), able to understand the English language, had a life expectancy of six months or greater, and had never received chemotherapy. Initially only those with lung cancer and breast cancer were being considered as participants. However, after slow accrual, the study was opened to all participants with cancer who were receiving chemotherapy for the first time.

A non randomized convenience sample was utilized. Each participant who met the inclusion criteria was asked to participate in the study by trained nursing staff at one of the participating six infusion centers during the data collection period. Only those who volunteered to participate were included in the study. The sample consisted of 55 eligible participants who were willing to participate. A final sample of 32 eligible participants completed the entire study and make up the sample for this study. These participants ranged in

age from 23 to 73 years. Thirty-four percent of the participants were male while 65.6% were female.

Protection of Human Subjects

Prior to collection of data, permission was obtained from the Institutional Review Board (IRB) of Texas Oncology, P. A. (Appendix A), the company from which the participants were recruited. When two additional data collection sites were added to the study, a second letter of permission was obtained from the IRB of Texas Oncology, P. A. (Appendix B). Permission was also obtained from the Human Subjects Review Committee at Texas Woman's University (Appendix C). Finally, approval to conduct the study was obtained from the Graduate School at Texas Woman's University (Appendix D).

All participants signed a consent form (Appendix E and F) that described the purpose of the study and the study procedures. The consent also assured subject confidentiality, anonymity, and absence of penalties with withdrawal from the study. The consent also listed several phone numbers including a pager number to reach the researcher should the participant have a question regarding the

study. A copy of the consent form was given to each subject to keep for his or her records once it was signed. A cover letter accompanying each questionnaire packet reiterated the purpose of the study, the estimated time for completion of the packet, and a reminder that participation in the study was strictly voluntary.

Procedures

The researcher consulted the research department of Texas Oncology, P. A. to obtain assistance with IRB approval and recruitment of data collection sites. With the assistance of the research staff four sites agreed to participate in the study. The IRB required that these sites be named on the consent form (Appendix E and F). Also required on the consent form was a name of a physician at each data collection site who would be willing to be a co-investigator for the study. This individual was responsible for assisting with study accrual, study explanation to potential participants, and signing of the consent declaring informed consent had been made.

After IRB approval was obtained, the researcher conducted training sessions for the infusion center nursing staff who would be assisting with the study. The training sessions included a presentation about the study and a presentation of the two packets that the nurses would be presenting to the participants. Step by step instructions were given regarding proper presentation of the study to potential participants and role playing was conducted. A question and answer session concluded each training session. The researcher also reinforced the use of the pager to reach the researcher with any questions that arose during the study. Written information about the study and the information covered at the training sessions was given to each infusion center nurse to reinforce the training session. Two sites received in person training sessions while two other sites received training sessions via teleconference. This was due to the long distance of two sites from the researcher. When the two additional data collection sites were added, training sessions as described above were repeated for their infusion center nursing staff.

Letters introducing the study and encouraging accrual were sent to each participating sites' physicians and nursing staff not attending the training sessions. This assured that the entire medical staff at each site was aware of the study. It also helped the infusion center nursing staff identify potential participants who were eligible for the study. Ample communication assisted acceptance and success of the study in the clinic environment where research studies were not commonly conducted.

Once the study was approved by the IRB and open to accrual of participants, the researcher delivered study packets to each site. Each packet was labeled with a participant identification code number to facilitate confidentiality. Potential participants were approached by the trained infusion center nursing staff and asked if they would participate in the study. If they agreed to participate, the participants read and signed the consent form. The nurse then signed the consent form as a witness. Next, each participant read the cover letter that presented a review of the study and provided instruction for completion of the two questionnaires included in the packet. When the participant finished answering the questionnaires,

the cover letter instructed the participant to return it to the nurse who placed it in a predetermined location for pick up by the researcher. The researcher contacted each data collection site via phone or in person at least once a week to answer any questions the site staff may have and to collect data that were completed. Staff at the two sites in south Texas mailed their completed packets once a week by Federal Express to the researcher.

When a completed packet was received, the researcher reviewed the participant's medical record to complete part I of the Chemotherapy Knowledge Questionnaire (Appendix G). This was performed to verify the answers the subjects provided on part II of the Chemotherapy Knowledge Questionnaire (CKQ) (Appendix H). The infusion center nurses at the two sites in south Texas provided copies of the pertinent medical forms for those placed on the study at their locations in order for the researcher to complete part I of the CKQ.

The second questionnaire packet was completed by each study participant prior to his or her third cycle of chemotherapy. The researcher delivered the second packet to the data collection site one week before the third cycle of chemotherapy was scheduled to be

administered. The second questionnaire packet contained a cover letter that repeated the purpose of the study and reiterated that the study was strictly voluntary. The second packet also contained two questionnaires for the participants to complete. The completed packet was then picked up by the researcher the following week. Weekly contact with each data collection site was maintained by the researcher to assure that the staff had their questions answered timely and continued support for the study was evident.

After 55 eligible participants were placed in the study, the study was closed to further accrual. This number was chosen to assure that a minimum of 30 participants would complete the entire study, allowing for attrition. Each site was contacted by letter and by phone to notify them that the study was closed to further accrual. Unused packets were picked up or mailed to the researcher in the case of the south Texas sites.

Instrumentation

One instrument and two demographic inventories were used to collect data: (a) the Chemotherapy Knowledge Questionnaire (CKQ)

(Appendix H), (b) the Demographic Inventory I (Appendix I), and (c) the Demographic Inventory II (Appendix J).

The Chemotherapy Knowledge Questionnaire (CKQ) was utilized in the study to determine the first time chemotherapy recipient's knowledge of chemotherapy. A review of the literature revealed only one questionnaire available to collect data for this study, the CKQ. The first part of the CKQ (Appendix G) was completed by the researcher who gathered information from the participant's medical record regarding location of treatment, participant's diagnosis, treatment purpose, and chemotherapy agents prescribed. The information obtained was used to validate the answers the participant provides on the second part of the CKQ.

The second part of the CKQ asked the participant to identify the purpose of their chemotherapy treatment, the names of their chemotherapy drugs, and the potential side effects that could occur from their chemotherapy treatment as well as the side effects that did occur as a result of their chemotherapy treatment.

The participants identified their chemotherapy drugs from a list of 35 possible choices. An "other" category was included to allow

subjects to write in a name. During the first administration of the CKQ the participants were asked to indicate on a list of 43 potential side effects of chemotherapy those that could occur from their chemotherapy treatment. At the second administration of the CKQ the participants also identified the actual side effects that occurred.

The chemotherapy knowledge score was a combination of the drug name accuracy score and the potential side effects score. The drug name accuracy score was obtained by dividing the number of drug names correctly identified by the number of drugs the participant took. The potential side effects score was the sum of the potential side effects correctly identified and the irrelevant side effects not selected, making it a total possible score of 43 regardless of the actual number of relevant side effects for the participant's chemotherapeutic regimen. This method corrected for any error introduced by the participant's guessing and duplicates the method followed by Dodd (1984) in a similar study.

The original CKQ was developed by Muss et al. (1979) and modified by Dodd and Mood (1981). Reliability and validity data were stated as being completed for the modified CKQ (Dibble,

personal communication, September 1995; Dodd, 1984). The CKQ is currently written to be administered by an interviewer. However, for the purpose of this study, the CKQ was modified to be a self-administered questionnaire. A copy of the modified CKQ was obtained from Marylin Dodd, RN, Ph.D., FAAN, it's author, as well as permission to use and modify the CKQ (Appendix K). Dr. Dodd was reached at the University of California in San Francisco in the Department of Physiological Nursing at the School of Nursing.

Modification of the CKQ was necessary to update the questionnaire as well as to convert it into a self-administered tool. Questions about the participant's performance status and frequency of hospitalization were not pertinent to this study and therefore, were eliminated from part I of the CKQ. The first question of part II asked participants to state the purpose of their treatment. Though this question was not directly linked to the study's hypotheses or research questions, the question was retained to help maintain reliability and validity previously determined by Dodd (1984).

After the questions were re-worded to reflect the requirements of a self-administered questionnaire and the

chemotherapy agents and side effects listed in the questionnaire were updated to reflect current therapy regimes, the CKQ was sent to three oncology experts to be evaluated for content validity. The three individuals were instructed to address the clearness and appropriateness of each question included in the CKQ. The three experts were also given a copy of the cover letter prepared for packet #1 (Appendix L) and packet #2 (Appendix M) to evaluate because the cover letters contained the instructions for completion of the CKQ. Of the three individuals selected to evaluate the CKQ, only two, Monica White, RN, MS, AOCN and Joni Mokry, RN, BSN, OCN, responded to the evaluation request even though verbal consent to participate was obtained from all three. The third individual failed to return the evaluation following requests to do so by three letters and two phone calls. With only two respondents, changes recommended by both individuals were made. After the changes were made the modified CKQ was sent to the two oncology experts one last time to assure that the necessary changes were made. The CKQ found in Appendix H reflects the final draft obtained after the last verification of content validity.

The researcher met with the patient education coordinator for Texas Oncology, P. A., the data collection site's managing company, prior to initiation of the study to verify the side effect recall list for each chemotherapy agent found on the CKQ (Appendix H). This was completed to eliminate any chance of bias when evaluating the answered CKQ by the researcher. The list developed for each chemotherapy agent was based on the standard education information commonly presented to each subject verbally and in writing prior to the initiation of chemotherapy treatments by Texas Oncology, P. A. clinics.

The Demographic Inventory I (Appendix I) was a researcher-developed instrument used to collect demographic information of the first time chemotherapy recipient that were independent variables of the study. Data collected from this inventory included the following items: (a) age, (b) gender, (c) previous receipt of chemotherapy, (d) education attainment, (e) receipt of educational information, (f) ability to understand the educational information, and (g) usefulness of the educational information. Only those who answered no to receiving chemotherapy in the past, question #3 on

the Demographic Inventory I, were considered eligible to participate in this study. One open-ended question was included on this inventory for the subject to comment about ways to improve the educational information they received. A total of 13 questions were asked on this inventory. The Demographic Inventory I was administered with the first packet immediately following the chemotherapy education session prior to the first chemotherapy treatment.

The Demographic Inventory II (Appendix J) was also a researcher-developed instrument and was used to collect demographic information of the first time chemotherapy recipients prior to their third cycle of chemotherapy. The instrument asked four questions and gained information about the frequency of participant's contact with their oncologist during their chemotherapy treatments, the most common reason for the call(s) to their oncologist, and who did they speak with most frequently when they did call their oncologist. The participants were also asked if they would be receiving their third course of chemotherapy that day. This question did not directly address the hypotheses or research

questions of this study but did provide information about the participant's treatment protocol and frequency knowledge.

Treatment of Data

Only those participants who completed each questionnaire completely for both data collection points were considered for inclusion in the data analysis of this study. Fifty-five participants were eligible to participate in the study during the data collection period. However, only 32 completed the entire study and were considered for data analysis. Attrition from the study was planned for and expected. Reasons for attrition included: death, change of chemotherapy treatment plan (either change in chemotherapy agents or stopping of treatment completely), failure to complete one or more questions in the questionnaire packet, movement of treatment to another location, missed by infusion center staff at the second data collection point, and failure of the subject or infusion center staff to sign the consent correctly and/or completely.

One coding decision was made by the researcher to correct an error noted on the Demographic Inventory II (Appendix J) after it

was distributed for the study. Question 4 on the Demographic Inventory II provided four options for the participants to answer but there should have been a fifth answer, "not applicable, I did not call my oncologist." This answer was relevant for six of the 32 participants. Four of the participants left the answer to question 4 blank as a result of the error while two answered question 4. For the purposes of coding the question, the four who left question 4 blank where coded as if a fifth choice of "not applicable, I did not call my oncologist", was available. The two who did choose an answer were coded as such. Their erroneous answers were not significant to the findings.

The study utilized descriptive analysis of data that included percentages, frequencies, and means. These were used to answer the research questions for this study. A t-test was utilized to determine acceptance or rejection of null hypothesis 1 while Pearson r was utilized to determine acceptance or rejection of null hypothesis 2. A significance level of .05 was utilized on all parametric tests. The Statistical Package for the Social Sciences, SPSS-X, software program was utilized to analyze the data.

CHAPTER 4

FINDINGS

The purpose of the study was to determine the difference between the chemotherapy knowledge score obtained immediately following the chemotherapy education and prior to the third cycle of chemotherapy for Texas area first time chemotherapy recipients. The descriptive data of participants, statistical analyses of results, as well as additional findings are reported in this chapter. Descriptive analysis of data included the use of percentages, frequencies, ranges, and means. Parametric tests were utilized for the hypotheses including a t-test to answer hypothesis 1 and Pearson r to answer hypothesis 2.

Descriptive Characteristics of the Participants

The participants for this study were recruited between February and June of 1996 from six outpatient cancer centers located in Texas and managed by Texas Oncology, P. A. The target population

of this study was first time recipients of chemotherapy with a diagnosis of cancer. Each participant was 18 years or older, physically able to participate, mentally competent (able to complete the instrument), able to understand the English language, had a life expectancy of six months or greater, and had never received chemotherapy. During the data collection period 55 eligible participants were willing to participate. A final sample of 32 eligible participants completed the entire study and make up the sample for this study. This provided a completion rate of 58% with 42% attrition. Attrition from the study was planned for and anticipated. Table 1 presents the status of the causes of attrition of this sample. No participant failed to complete the study due to voluntary withdrawal.

The final sample of 32 participants who completed the entire study including two separate questionnaire packets ranged in age from 23 to 73 years with a mean of 52.4 years (SD = 14.4). Eleven participants were male (34.4%) while 21 were female (65.6%). The participants were asked to report their highest level of educational attainment on the Demographic Inventory I (Appendix I). The

minimum level of education for the participants was eight years of schooling and the

Table 1

Attrition of Sample (N=23)

Cause of Attrition	Frequency	%
Death	1	4.3
Failed inclusion criteria	5	21.7
Stopped or changed treatment	11	47.8
Incomplete forms	3	13
Missed by staff	3	13
Total	23	100.0

maximum level of education was 19 years. The mean was 13. 75 years (SD = 2.62). Approximately 85% of the participants had a minimum of a high school diploma or an equivalent. Table 2 provides the frequency of educational attainment.

The participants had a variety of cancer diagnoses but breast cancer was the most frequently represented diagnosis of cancer in

the study (n = 13). The next most frequent diagnosis was colon and lung cancer with five each. Three participants had a diagnosis of lymphoma. Liver cancer,

Table 2

Level of Education (N = 32)

Years of School Completed	Frequency	%
8	2	6.3
11	3	9.4
12	7	21.9
13	2	6.3
14	6	18.8
15	2	6.3
16	6	18.8
17	2	6.3
18	1	3.1
19	1	3.1
Total	32	100.0

pancreatic cancer, appendix cancer, gallbladder cancer, uterine cancer, and testicular cancer each had one participant with this type of cancer. Several different chemotherapy agents and protocols were represented in this study due to the variety of cancer diagnoses noted above. Diagnosis frequencies are documented in Table 3.

Each questionnaire packet asked the participants to document the purpose of their treatment. At the first administration of the questionnaire packet, 24 participants (75%) stated that the purpose of their treatment was cure, 5 participants (15.6%) thought that their treatment was for disease control, and 3 participants (9.4%) were unsure of treatment purpose. When the question was repeated during the second questionnaire packet, 62.5 % of the participants (n = 20) believed their treatment was for disease cure, 31.3% of the participants (n=10) thought their treatment was for disease control, and 6.3% of the participants (n = 2) were unsure of the treatment purpose.

Following administration of the first questionnaire packet, each participant's medical record was reviewed to verify their responses to the questionnaire. Eighteen participants (56.3%) correctly stated

their treatment purpose while 14 participants (43.8%) did not know

Table 3

Cancer Diagnosis of Participants (N = 32)

Diagnosis	Frequency	%
Breast Cancer	13	40.6
Colon Cancer	5	15.6
Lung Cancer	5	15.6
Lymphoma	3	9.4
Liver Cancer	1	3.1
Pancreatic Cancer	1	3.1
Appendix Cancer	1	3.1
Gallbladder Cancer	1	3.1
Uterine Cancer	1	3.1
Testicular Cancer	1	3.1
Total	32	100.0

the correct reason for their treatment. An answer of unsure was considered an incorrect response to the question. At the second data collection point, 17 participants (53.1%) were aware of their

treatment purpose and 15 subjects (46.9%) incorrectly stated their treatment purpose.

Study Findings

Data were analyzed using the Statistical Package for the Social Sciences, SPSS-X, (SPSS, Inc., 1990) software program to answer four research questions and test two hypotheses for this study. Each research question and hypothesis will be listed below followed by the results obtained during the data analysis.

Research Question 1: How many first time chemotherapy recipients report side effects that are not related to their chemotherapy treatment?

This research question was answered by the data obtained from question 4 on the Chemotherapy Knowledge Questionnaire (CKQ) (Appendix H). This question asked participants to mark side effects that they actually experienced while undergoing chemotherapy treatment. The side effects documented on this question by each participant was compared to the list of side effects that were likely to occur due to the chemotherapy agents the

participant was receiving. Only nine participants were able to correctly credit side effects to their chemotherapy agents. The remaining 23 participants credited 1 to 9 side effects inappropriately to chemotherapy. The mean number of incorrectly documented side effects was 2.25 (SD = 2.652). Table 4 presents the frequency of inappropriately credited side effects to chemotherapy. The actual

Table 4

Inappropriately Credited Side Effects (N = 32)

Number of Inappropriate Side Effects Reported	Frequency	%
0	9	28.1
1	8	25
2	6	18.8
3	3	9.4
5	1	3.1
6	1	3.1
7	2	6.3
9	2	6.3
Total	32	100.0

number of side effects reported by participants for this question ranged from 2 to 21 with a mean of 7.594 side effects (SD = 4.528) experienced by participants.

Research Question 2: How many first time chemotherapy recipients will report they are able to read and understand the educational information they received about their chemotherapy treatment?

Before determining the knowledge level of first time chemotherapy recipients, it was important to know if they could understand the educational information that was used to provide the knowledge. The Demographic Inventory I (Appendix I) listed several questions that provided the answer to this research question. All participants said that they received written and verbal educational information about their chemotherapy treatment. Twenty-nine participants (90.6%) reported they were able to read the written educational information that they received while only three subject (9.4%) reported they were not able to read the written materials. All participants stated being able to understand the

verbal educational information they were given about their chemotherapy treatment. Thirty subjects (93.8%) documented that they were able to understand the written educational information provided about their chemotherapy treatment. Only two (6.3%) said they were not able to understand the written information.

Research Question 3: How useful will the first time chemotherapy recipients find the educational information they receive about their chemotherapy treatment?

During the first data collection point participants were asked on the Demographic Inventory I (Appendix I) about the usefulness of the educational materials they received in order to determine the value placed on the chemotherapy education provided. Only one participant said that the information provided was not new information for him. The remaining 31 had not received any other formal chemotherapy education. The participants were asked how useful they found the written and the verbal educational information they received about their chemotherapy treatment. No participants stated the information was not useful. Fourteen (43.8%) subjects found the written information useful while 18 (56.3%) subjects found

the written information very useful. Six participants (18.8%) found the verbal educational information useful and 26 participants (81.3%) found this information very useful.

One open ended question requested that the participants indicate what could be done to improve the educational information they received. Fifteen participants wrote "nothing" or "none" indicating that they recommended no changes in the educational information they received. Another 13 participants left the question blank. The question may have been left blank by many of the participants due to the length of the questionnaire or due to the participants' apprehension of initiating their first chemotherapy treatment. The reason for the blank responses was not investigated. Table 5 presents the response to this question.

Research Question 4: How frequently will first time chemotherapy recipients contact their oncologist regarding side effect management issues during their chemotherapy treatment?

This question was asked to assess the frequency of side effect occurrence for participants of the study. It also helped identify if

Table 5

Improvements for the Educational Information (N = 32)

Recommended Changes to Educational Information	Frequency	%
Make no changes	15	46.9
Left blank	13	40.6
Give more on nausea and fatigue	1	3.1
Provide a videotape	1	3.1
Provide slides and/or photos	1	3.1
Don't know	1	3.1
Total	32	100.0

participants could recognize side effects and the behavior they took there after. Questions located on the Demographic Inventory II (Appendix J) addressed phone calls made to the oncologist. Twenty-five participants (78.1%) called the oncologist 1 to 4 times during their chemotherapy treatment. Six subjects (18.8%) said they had never needed to call the oncologist during their chemotherapy treatment. No participants chose the response of 5 to 8 calls and 1

participant (3.1%) called 9 or more times. The mean number of phone calls made to the oncologist was 1.875 (SD = 0.554).

Participants most frequently spoke with the oncologist's nurse when they did call the oncologist (and/or cancer center). Seventeen participants (53.1%) spoke with the oncologist's nurse to answer their questions, 5 (15.6%) spoke with the appointment secretary, 4 (12.5%) spoke with the oncologist, 2 (6.3%) spoke with the infusion center nurse, and 4 (12.5%) left the answer blank because they had not called the oncologist and this particular question was missing a not applicable option which was available on the other two questions which addressed the phone calls the participants made to the oncologist. Table 6 depicts the reason why the participants called their oncologist. An "other" category was also provided as an answer to this question with a blank line for the participants to fill in an answer. Five participants chose this option. Three participants called for non chemotherapy related symptoms, one subject called for x-ray results, and another subject called to verify compatibility of a new prescription received from another doctor with the chemotherapy agents the oncologist was prescribing.

Table 6

Reasons for Calling Your Oncologist (N = 32)

Reason to Call the Oncologist	Frequency	%
Side effect management issues	16	50.0
Not applicable, did not call	6	18.8
Other	5	15.6
Appointment information	4	12.5
Laboratory information	1	3.1
Total	32	100.0

Hypothesis 1: There will be no statistically significant difference between the chemotherapy knowledge score of the Texas area first time chemotherapy recipients taken immediately following the chemotherapy education and the score taken prior to the third cycle of chemotherapy.

The chemotherapy knowledge score was a combination of the drug name accuracy score and the potential side effects score. The drug name accuracy score was obtained by dividing the number of drug names correctly identified by the number of drugs the

participant took. The potential side effects score was the sum of the potential side effects correctly identified and the irrelevant side effects not selected, making it a possible score of 43 regardless of the actual number of relevant side effects for the participant's chemotherapeutic regimen. This method corrected for any error introduced by guessing. Each of the drug name accuracy scores as well as each of the potential side effects score taken at two data collection points were compared. Also, the chemotherapy knowledge score was determined for each data collection point. The raw scores were converted to z scores in order to complete a t-test analysis.

Each questionnaire packet that the participants answered requested that the participants identify the names of the chemotherapy agents they were receiving and the side effects that were likely to occur as a result of receiving the chemotherapy agents. Table 7 provides a summary of the t-test results conducted on the drug name scores and the side effects score. Prior to the first cycle of chemotherapy, 27 participants (84.4%) were able to identify all their chemotherapy drug names correctly. Three participants (9.4%)

identified two out of three correctly while two participants (6.3%) were not able to identify any of their chemotherapy drug names correctly. When the questionnaire was administered prior to the participants' third cycle of chemotherapy 27 subjects (84.4%) were able to correctly identify all their chemotherapy drug names, two

Table 7

Analysis of t-test of the Drug Name Score and the Side Effects Score Taken at Two Data Collection Points

Variable	X	SD	Minimum	Maximum	t value	2 tail prob.
Drug Name Score						
Before first tx	90.66	25.70	0	100	.09	.930
Before third tx	90.13	26.37	0	100		
Side Effects Score						
Before first tx	34.34	4.88	16	39	.83	.416
Before third tx	33.63	2.72	27	40		

participants (6.3%) named two out of three drug names correctly, one participant (3.1%) identified half of their chemotherapy drug names

Table 8

Side Effects Score Before the First and the Third Cycle of Chemotherapy (N =32)

Side Effects Score Before First Cycle	Frequency	%	Side Effects Score Before Third Cycle	Frequency	%
39	4	12.5	**40**	1	3.1
38	3	9.4	**38**	1	3.1
37	7	21.9	**37**	2	6.3
36	3	9.4	**36**	4	12.5
35	4	12.5	**35**	4	12.5
34	2	6.3	**34**	3	9.4
33	2	6.3	**33**	7	21.9
31	2	6.3	**32**	5	15.6
28	3	9.4	**31**	2	6.3
26	1	3.1	**29**	2	6.3
16	1	3.1	**27**	1	3.1
Total	32	100.0	Total	32	100.0

correctly, and two participants (6.3%) were not able to correctly identify any of their chemotherapy drug names. The side effects score for the participants prior to their first cycle of chemotherapy ranged from 16 to 39 side effects correctly identified. The range for the second data collection point was from 27 to 40. A score of 43 is a perfect score. Table 8 presents the frequencies of side effect scores for both data collection points.

Table 9 presents the summary of the t-test results of the chemotherapy knowledge score based on z scores. A significance of .05 was utilized for all parametric tests. No statistical significance was found with the t-test analysis.

Table 9

Analysis of t-test for the Chemotherapy Knowledge Score

Variable	X	SD	t value	2 tail prob.
Chemotherapy Knowledge Score before first cycle of chemotherapy	125.0	26.931	.22	.83
Chemotherapy Knowledge Score before third cycle of chemotherapy	123.75	27.424		

Hypothesis 2: There will be no relationship between the number of phone calls made by the first time chemotherapy recipient to their oncologist and the first time chemotherapy recipient's chemotherapy knowledge score taken prior to the third cycle of chemotherapy.

If the participants were experiencing more side effects and contacting the oncologist frequently, would they recall more side effects and therefore, have a higher chemotherapy knowledge score as compared to participants calling less and experiencing less side effects? The participants were asked about their phone call habits on the Demographic Inventory II (Appendix J) which was included in the second questionnaire packet. The chemotherapy knowledge score was determined by adding the drug name score and the side effects score from the second questionnaire packet and converting the raw score to a z score. Pearson r correlation coefficient was used to evaluate relationships between the number of phone calls made by the first time chemotherapy recipients to their oncologist and the first time chemotherapy recipient's chemotherapy knowledge score

taken prior to the third cycle of chemotherapy. A very slight but not statistically significant negative correlation was found, -.0701.

Additional Findings

Additional findings were noted following data analysis. These include the frequency of side effect recognition for 9 commonly occurring side effects and the percentage of participants that were able to correctly identify the cycle of chemotherapy they were preparing to receive.

The participants were provided 43 possible side effects in which to choose the side effects that occur with their specific chemotherapy agents they are receiving. Several side effects included in this list commonly occur with nearly all chemotherapy drugs. Nine such side effects were reviewed to see if the participants identified them as possible side effects that could occur due to the chemotherapy drugs they are receiving. The side effects include: infection, bleeding, hair loss, low blood counts, fever, nausea/vomiting, fatigue, anorexia, and taste changes. Whether or not the participants experienced the side effect was also assessed.

Table 11 presents the frequency of the recalled side effects prior to the first cycle of chemotherapy, prior to the third cycle of chemotherapy, and whether or not the participant actually experienced the side effect during their chemotherapy treatment.

The first question on the Demographic Inventory II (Appendix J) included in the second questionnaire packet asked the participants if the treatment they would be receiving was their third cycle. This question determines if the participant was aware of the cycle being administered next and shows the participants' understanding of their treatment scheduling. The researcher followed the participant's chemotherapy schedule via computer and in order to have received the second questionnaire packet, the participant would have been due for their third cycle of chemotherapy following the completion of the questionnaire packet. Twenty-five (78.1%) participants correctly stated that they would be receiving their third cycle while 7 (21.9%) participants stated that they would not be receiving their third cycle

Table 10

Recall of Commonly Occurring Side Effects of Chemotherapy (N = 32)

Side Effect	Yes/No (Y) (N)	Before First Tx Freq.	%	Before Third Tx Freq.	%	Experienced Side Effect Freq.	%
Infection	Y	18	56.3	9	28.1	2	6.3
	N	14	43.8	23	71.9	30	93.8
Bleeding	Y	9	28.1	7	21.9	3	9.4
	N	23	71.9	25	78.1	29	90.6
Hair Loss	Y	28	87.5	27	84.4	21	65.6
	N	4	12.5	5	15.6	11	34.4
Low counts	Y	31	96.9	27	84.4	19	59.4
	N	1	3.1	5	15.6	13	40.6
Fever	Y	14	43.8	13	40.6	8	25
	N	18	56.3	19	59.4	24	75
Nausea/ Vomiting	Y	28	87.5	27	84.4	21	65.6
	N	4	12.5	5	15.6	11	34.4
Fatigue	Y	26	81.3	26	81.3	22	68.8
	N	6	18.8	6	18.8	10	31.3
Anorexia	Y	18	56.3	16	50	12	37.5

Side Effect (cont.)	Yes/No	Before First Tx		Before Third Tx		Experienced Side Effect	
		Freq.	%	Freq.	%	Freq.	%
Anorexia (cont.).	N	14	43.8	16	50	20	62.5
Taste Change	Y	10	31.3	15	46.9	13	40.6
	N	22	68.8	17	53.1	19	59.4

of chemotherapy on the day they were completing the questionnaire packet.

Summary of Findings

Four research questions were answered and two hypotheses were tested. Descriptive data for demographic information of the subjects, statistical analyses of the results, and additional findings were presented. The next chapter will discuss and analyze the findings in detail.

CHAPTER 5

SUMMARY, DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

This chapter presents concluding information that will be introduced under the following headings: (a) Summary of the Study, (b) Summary of the Findings, (c) Summary of the Discussion and Conclusions, and (e) Recommendations.

Summary of the Study

This study was implemented to examine the amount of information retained by cancer patients about their chemotherapy treatment after receiving chemotherapy education in an outpatient setting. This study also examined knowledge retention over time for first time chemotherapy patients. The purpose of the study was to determine the difference between the chemotherapy knowledge score obtained immediately following the chemotherapy education and prior to the third cycle of chemotherapy for Texas area first time

chemotherapy recipients. Demographic characteristics of the first time chemotherapy recipients was collected and examined as well.

This study was conducted during the first half of 1996. Fifty-five participants agreed to participate and 32 eligible participants completed the entire study and made up the sample considered in this study. Each participant completed two questionnaire packets. The first packet was completed following the chemotherapy education just prior to the first chemotherapy treatment. This packet included a cover letter with packet completion instructions, a researcher developed inventory, the Demographic Inventory I, and the Chemotherapy Knowledge Questionnaire developed by Muss et al. (1979) and modified by Dodd and Mood (1981). The second questionnaire packet was administered prior to the participant's third cycle of chemotherapy. This packet included a cover letter, a second researcher developed inventory, the Demographic Inventory II, and the Chemotherapy Knowledge Questionnaire.

Descriptive techniques such as frequencies, ranges, means, and percentages were used in data analysis. Parametric tests were

utilized for the hypotheses including a t-test to test hypothesis 1 and Pearson r to test hypothesis 2.

Summary of Findings

The target population of this study was first time recipients of chemotherapy with a diagnosis of cancer that were recruited from six outpatient cancer centers located in Texas. The 32 participants who completed the entire study ranged in age from 23 to 73 years with a mean of 52.4 years. The minimum level of education for the participants was 8 years of schooling and the maximum level of education was 19 years. The mean was 13.75 years of education.

The participants had a variety of cancers but breast cancer was the most frequently represented diagnosis of cancer in the study ($\underline{n}$ = 13). The next most frequent diagnoses were colon and lung cancer with five each. Three participants had lymphoma, while liver cancer, pancreatic cancer, appendix cancer, gallbladder cancer, uterine cancer, and testicular cancer were present in one participant.

Each questionnaire packet asked the participants to state the purpose of their chemotherapy treatment. Eighteen participants

(56.3%) correctly stated their treatment purpose while 14 participants (43.8%) did not know the correct reason for their treatment when asked at the first data collection point. Following the second questionnaire 17 participants (53.1%) were aware of their treatment purpose and 15 participants (46.9%) incorrectly stated their treatment purpose.

Utilizing the Statistical Package for the Social Sciences, SPSS-X, four research questions were answered and two hypotheses were tested. The data analysis revealed the following:

1. Research Question 1: How many first time chemotherapy recipients report side effects that are not related to their chemotherapy treatment?

Only nine participants were able to correctly credit side effects to their chemotherapy agents. The remaining 23 participants credited 1 to 9 side effects inappropriately to their chemotherapy treatment. The mean number of incorrectly documented side effects was 2.25 (SD = 2.65). The actual number of side effects reported by the participants ranged from 2 to 21 with a mean of 7.59 side effects experienced by the participants.

2. Research Question 2: How many first time chemotherapy recipients will report they are able to read and understand the educational information they received about their chemotherapy treatment?

Twenty-nine participants (90.6%) were able to read the written educational information that they received. Thirty participants (93.8%) documented that they were able to understand the written educational information provided to them about their chemotherapy education.

3. Research Question 3: How useful do first time chemotherapy recipients find the educational information they received about their chemotherapy treatment?

Fourteen (43.8%) participants found the written educational information useful while 18 (56.3%) participants found the written information very useful. Six participants (18.8%) found the verbal educational information useful and 26 participants (81.3%) found this information very useful. No participants stated the information was not useful.

4. Research Question 4: How frequently do first time chemotherapy recipients contact their oncologist regarding side effect management issues during their chemotherapy treatment?

Twenty-five participants (78.1%) called the oncologist 1 to 4 times during their chemotherapy treatment. Six participants (18.8%) had never called the oncologist during their chemotherapy treatment and one participant (3.1%) called 9 or more times. The mean number of phone calls made to the oncologist was 1.875 (SD = 0.554). When calling the participants most frequently spoke with the oncologist's nurse (53.1%) and they most often called regarding side effect management (50%).

5. Hypothesis 1: There is no statistically significant difference between the chemotherapy knowledge score of the Texas area first time chemotherapy recipients taken immediately following the chemotherapy education and the score taken prior to the third cycle of chemotherapy.

The chemotherapy knowledge score was a combination of the drug name accuracy score and the potential side effects score. The data analysis indicates that the study failed to reject the hypothesis.

6. Hypothesis 2: There is no relationship between the number of phone calls made by first time chemotherapy recipients to their oncologist and first time chemotherapy recipient's chemotherapy knowledge score taken prior to the third cycle of chemotherapy.

A Person r correlation coefficient was used to evaluate the relationships between the number of phone calls made by the first time chemotherapy recipients and the chemotherapy knowledge score taken prior to the third cycle of chemotherapy. Findings indicate failure to reject hypothesis 2.

Two additional findings were noted following data analysis. The first assessed the frequency of side effect recognition for 9 commonly occurring side effects and the second addressed the percentage of participants that were able to correctly identify the cycle of chemotherapy they were preparing to receive. Of the 43 possible side effects the participants were provided on the Chemotherapy Knowledge Questionnaire 9 side effects common to nearly each chemotherapy agent were evaluated individually to determine if the participants recognized them as side effects that

could occur as a result of receiving their chemotherapy. Hair loss and low blood counts were recognized most frequently as possible side effects that patients may experience even if they did not actually experience the side effects. However, a life threatening side effect such as infection was recognized as a potential side effect by 18% of the participants at the first data collection point and only by 9% of the participants before their third chemotherapy treatment. Bleeding was named a potential side effect by 9% of the participants prior to their first chemotherapy treatment and by 7% of the participants at the second data collection point. Other common side effects were recalled approximately 50% of the time.

On Demographic Inventory II, the participants documented whether or not it would be their third cycle of chemotherapy they would be receiving after completing the questionnaire packet. Twenty-five (78.1%) participants correctly stated their treatment schedule while 7 (21.9%) said they were not receiving their third cycle of chemotherapy, indicating lack of treatment schedule knowledge.

Summary of the Discussion and Conclusions

This study closely replicated two previous studies (Dodd & Mood, 1981; Muss et al., 1979). However, both studies are dated and both indicated that chemotherapy recipients retained little of the information provided to them during informed consent and education about their treatment. Indication for replicating these studies and examining present day educational programs was apparent.

After data analysis, comparisons of this study were made to the previous studies. Similarities as well as some differences in the results were observed. Muss et al. (1979) utilized 100 breast cancer patients who may or may not have received chemotherapy previously and Dodd and Mood (1981) used 30 patients with a variety of cancer initiating chemotherapy for the first time. This study used chemo-naive participants with various diagnoses of cancer and utilized similar inclusion criteria as seen in the Dodd and Mood (1981) study. Unlike the two previous studies, this study was conducted exclusively in an outpatient setting, included evaluation of

both physician and nursing education programs, and studied standard therapy protocols versus research protocols.

Fifty-five participants were placed on study after agreeing to participate but only 32 completed the entire study and were eligible for data analysis. A 42% attrition rate was noted and anticipated because the study was being conducted over time. The most common cause of attrition occurred due to a change or halt in the treatment regime (47.8%). Only three participants were missed by the staff distributing the packets in the clinics. This is important to note because the staff volunteered to participate in the study and none had previous training or experience in conducting and assisting with a research study. Frequent contact and reminders about the steps to take in conducting the study offered by the principal researcher appeared to help the staff gather the data and minimize loss of participants. No voluntary withdrawal of participants was experienced which indicated that the participants valued their inclusion in the study.

Initially only those diagnosed with breast cancer and lung cancer were planned to be included in the study. These two

diagnoses were chosen for a few reasons. These diagnoses represent the most common cancers treated in the outpatient setting and they are also the two most frequently occurring cancers in the United States. Also, their treatment regimes are similar in administration frequencies and toxicities which would help in data collection and analysis.

However, accrual of participants was slower than planned requiring the need to include other diagnoses. This weakened the ability to compare patient results because it was not entirely valid to compare a colon cancer patient's score to a lymphoma patient's score when the colon cancer patient received one chemotherapy agent and the lymphoma patient received six. Nevertheless, the findings of this study were still worthwhile to review and consider for clinical practice interventions.

In Muss et al.'s (1979) study, 29% correctly stated the purpose of their treatment was cure while 55% correctly stated the purpose was control. While this study did not evaluate the findings according to control and cure it did demonstrate similar results when comparing the two responses from this study to the Muss et al.

(1979) results. In this study, 56.3% participants stated the purpose of their treatment correctly while 43.8% answered incorrectly. Similar results were noted at the second data collection point. Twelve participants answered correctly at both data collection points and eight answered incorrectly on each questionnaire. Of those who answered incorrectly, most viewed their treatment as cure when it actually was for control. As in the Muss et al. (1979) study, these results demonstrate that the chemotherapy recipients are not aware of the purpose of their treatment and their awareness level does not change over time. Asking the question does not apparently trigger the participants to inquire if they are unsure. This may be a protective coping mechanism, especially with regard to the palliative purposes of treatment (Dodd & Mood, 1981).

Nine (28.1%) study participants correctly credited experienced side effects to their chemotherapy agents and the remaining 23 participants incorrectly associated 1 to 9 side effects to their chemotherapy treatment. An average of 2.25 incorrectly side effects was noted. Muss et al. (1979) reported 6 of 100 correctly identified experienced side effects with an average of 3.44 errors while an

average of 2.13 errors were noted by Dodd and Mood (1981). In each of these studies it appears that unrelated side effects experienced by patients during chemotherapy treatments are credited to their chemotherapy agents. Lack of knowledge is apparent and reinforces the need for continual reinforcement of the side effect educational information. Without adequate information, it is reasonable to assume that the management of self-care deficits will be ineffective or delayed (Dodd & Dibble, 1993).

While Dodd and Mood (1981) asked patients to report who provided their chemotherapy education and how they valued the information, the results were not covered in their published work. In this study two questions addressed this area, asking participants if they could read and understand the written information provided to them and if they could understand the verbal information provided to them by the nurse and physician. In addition, the usefulness of the chemotherapy education was solicited. Only three participant could not read the written information and two could not understand the written information. All participants understood the verbal education. Of note, the average education level of participants

was 13.75 years of schooling. The written brochures and pamphlets are written at a 6th grade level indicating that years of education does not equal reading level.

Each participant reported that the education information was either useful or very useful. The verbal information was found more useful than the written information indicating that the time the nurses and physicians spend with the participants is viewed as important and valuable. As healthcare downsizing continues due to attempts of cost containment, it is important to know what is effective and important to patients.

This study also looked at the frequency of contact the patient had with the oncologist and the oncologist's office between treatments to see if this has an impact on the participant's knowledge score over time. The majority of the patients only made 1 to 4 calls but 50% of these calls were regarding side effect issues. No significant correlation was noted between the frequency of phone calls and the knowledge score obtained at the second data collection point. This could be due in part to the low frequency of calls. Dodd and Mood (1981) found in their study that long term retention of

knowledge was low and Muss et al. (1979) found no difference in knowledge score between those who completed the questionnaire prior to their first treatment and those who had been receiving chemotherapy for up to 24 months.

This study also demonstrated that their was no statistical difference between the knowledge score obtained prior to the first treatment and the third treatment. It appears that the studies conducted using the CKQ demonstrate no change in knowledge over time. It is not known if knowledge is lost and regained between data collection points, however. The design of these studies are not able to capture this change of knowledge. Overall, it appears that knowledge is gained at the initial education session and it is maintained over time. Continuing to provide chemotherapy education prior to the initiation of chemotherapy is warranted.

Twenty-seven participants (84.4%) were able to correctly identify the chemotherapy agents they were receiving at each data collection point. A chemotherapy knowledge score mean of 90.66% was observed following the first questionnaire and a chemotherapy knowledge score mean of 90.13% was noted on the second

questionnaire. These scores are significantly higher than those reported by Muss et al. (1979) and Dodd and Mood (1981) who observed an average of 60% and 30%, respectively. The number of agents the participants were receiving did not have any impact on the accuracy of recall. Perhaps changes in patient education programs offered to chemotherapy recipients over the years has improved. Because the data can not be generalized to all outpatient cancer patients, only the sites that participated in the study can be confident that the current information that their chemotherapy recipients are receiving about their chemotherapy agents is appropriate and adequate.

The same is not true of the side effect information, however. Participants correctly identified an average of 34.34 and 33.63 of 43 side effects at the first and second data collection points respectively. Again, there was not a statistically significant difference between the two scores. Experiencing the side effect did not have an impact on the participants' ability to recall the side effects. When assessing recall of specific side effects, only 18% of the participants said infection was a potential side effect on the first questionnaire and

only 9% acknowledged infection as a potential side effect on the second questionnaire. Recall was even worse for the side effect, bleeding. Nine percent and 7% of the participants recalled bleeding as a potential side effect at the first and second data collection point respectively. Less than 50% identified bleeding and infection as side effects in the Muss et al. (1979) study. Only 33% could identify infection as a side effect and none could identify bleeding as a side effect in the Dodd and Mood (1981) study. As seen in the previous studies, participants in this study were able to consistently recall distressing side effects such as nausea/vomiting (87.5% and 84.4%) and hair loss (87.5% and 84.4%), however, they were unable to identify the potentially lethal side effects, bleeding and infection. While the participants knew they would experience low blood counts (96.9% and 84.4%), they were not able to identify the consequence of low blood counts which is bleeding and infection.

Recommendations

The following recommendations are made for future investigations:

1. A larger sample size should be utilized among more outpatient sites in a duplication of this study to further clarify the knowledge retention of first time chemotherapy recipients.

2. When replicating this study in the future the researchers should consider limiting the cancer diagnoses of the chemotherapy recipients. By doing this, like treatment protocols will be considered and it will eliminate comparing single agent therapies to multiple agent protocols. This was initially planned for this study but was abandoned due to poor accrual numbers. Having more participating sites will help eliminate this issue.

3. The Chemotherapy Knowledge Questionnaire is the only tool currently available for use in a study of this kind that has been validated and tested for reliability. However, it is in need of updating and should be evaluated for further modification beyond what was done for this study to strengthen the tool. The changes will require re-validation and new reliability testing in order to assure it is a viable tool.

4. Results of this study should be used by the participating sites to strengthen current education programs provided to

chemotherapy recipients. Special attention should be paid during the educational process to assure the chemotherapy recipients understand the purpose of their treatment and the consequence of experiencing low blood counts (bleeding and infection). Previous studies as well as this study noted that patients could recall distressing side effects. Perhaps, the side effects of bleeding and infection should be presented in such a manner that patients understand the ramifications of these side effects by using terms to describe how patients would feel if such a side effect would occur. As key players in the education of chemotherapy patients, nurses can implement crucial steps to assure that the appropriate information is given to the chemotherapy recipients.

References

Dodd, M. (1982). Cancer patients' knowledge of chemotherapy: Assessment and informational interventions. Oncology Nursing Forum, 9(3), 39-44.

Dodd, M. (1983). Self-care for side effects in cancer chemotherapy: An assessment of nursing interventions-part II. Cancer Nursing, 6(1),63-7.

Dodd, M. (1984). Measuring informational intervention for chemotherapy knowledge and self-care behavior. Research in Nursing and Health, 7(1), 43-50.

Dodd, M. (1988). Efficacy of proactive information on self-care in chemotherapy patients. Patient Education and Counseling, 11(3), 215-225.

Dodd, M., & Dibble, S. (1993). Predictors of self-care: A test of orem's model. Oncology Nursing Forum, 20(6), 895-901.

Dodd, M., Dibble, S., & Thomas, M. (1993). Predictors of concerns and coping strategies of cancer chemotherapy outpatients. Applied Nursing Research, 6(1), 2-7.

Dodd, M., & Mood, D. (1981). Chemotherapy: Helping patients to know the drugs they are receiving and their possible side effects. Cancer Nursing, 4(8), 311-318.

Dougherty, L. & Stuttaford, J. (1993). Turning over a new leaflet. Nursing Times, 89(45), 46-48.

Fredette, S. (1990). A model for improving cancer patient education. Cancer Nursing, 13(4), 207-215.

Gorinchen, S. (1990). SPSS-X 3.0 [computer software]. The Netherlands: SPSS, Inc.

Hanucharurnkul, S. (1989). Predictors of self-care in cancer patients receiving radiotherapy. Cancer Nursing,12(1), 21-7.

Hiromoto, B. & Dungan, J. (1991). Contract learning for self-care activities: A protocol study among chemotherapy outpatients. Cancer Nursing, 14(3), 148-154.

Musci, E. & Dodd, M. (1990). Predicting self-care with patients and family members' affective states and family functioning. Oncology Nursing Forum, 17(3), 394-400.

Muss, H., White, D., Michielutte, R., Richards II, F., Cooper, M., Williams, S., Stuart, J., & Spurr, C. (1979). Written informed consent in patients with breast cancer. Cancer, 43(4), 1549-1556.

Myers, J., Davidson, J., Hutt, P., & Chatham, S. (1987). Standardized teaching plans for management of chemotherapy and radiation therapy side effects. Oncology Nursing Forum, 14(5), 95-99.

Nail, L., Jones, L., Greene, D., Schipper, D., & Jense, R. (1991). Use and perceived efficacy of self-care activities in patients receiving chemotherapy. Oncology Nursing Forum, 18(5), 883-887.

Reville, B., & Almadrones, L. (1989). continuous infusion chemotherapy in the ambulatory setting: The nurse's role in patient selection and education. Oncology Nursing Forum,16(4), 529-535.

Richardson, A. (1991). Theories of self-care: Their relevance to chemotherapy-induced nausea and vomiting. Journal of Advanced Nursing, 16(6), 671-676.

Sitza, J., Hughes, H., & Sobrido, L. (1995). A study of patients' experiences of side-effects associated with chemotherapy: Pilot stage report. International Journal of Nursing Studies, 32(6), 580-600.

Teich, C., & Raia, K. (1984). Teaching strategies for an ambulatory chemotherapy program. Oncology Nursing Forum, 11(5), 24-28.

APPENDIXES

APPENDIX A

Institutional Review Board Approval

(February 13, 1996)

Texas Oncology, P.A.

February 13, 1996

John Nemunaitis, M.D. & Pat Van Maanen, R.N., BSN, OCN
Texas Oncology, P.A.
3535 Worth Street
Dallas, Texas 75246

Dear Dr. Nemunaitis and Ms. Van Maanen::

The Texas Oncology Institutional Review Board has approved the protocol dated May, 1996 for the study "First Time Chemotherapy Recipients' Knowledge Following Chemotherapy Education." (IRB #96-03) which was presented at the February 6, 1996 meeting.

This letter also reflects approval of the Revised Consent document dated February 8, 1996.

The committee requires that the protocol be reviewed at one of the regular IRB meetings within one year of this date. We ask that you provide us with an update of your study at that time.

If there are any material changes in the investigation before the review, the committee requires notification.

The approval of the committee is based on your agreement not to initiate any changes in the approved research unless necessary to deal with an immediate hazard to a subject.

The committee requires that you report any unanticipated problems involving risk to human subjects or any noncompliance with the FDA Human Subject Regulations.

We wish you well with your worthy endeavors.

Sincerely,

Sherron Helms, M.D.
Alternate Chairman, Institutional Review Board
Texas Oncology, P.A.

APPENDIX B

Institutional Review Board Approval

(April 25, 1996)

APPROVED
FROM 5/1/96 TO 2/28/97

Texas Oncology, P.A.

Clinical Research

May 6, 1996

John Nemunaitis, M.D. & Pat Van Maanen, R.N., BSN, OCN
Texas Oncology, P.A.
3535 Worth Street
Dallas, Texas 75246

Dear Dr. Nemunaitis and Ms. Van Maanen::

The Texas Oncology Institutional Review Board has approved the Revised Consent dated 4/25/96 or the study "First Time Chemotherapy Recipients' Knowledge Following Chemotherapy Education." (IRB #96-03) which was presented at the February 6, 1996 meeting and approved on February 13, 1996

The Board notes that Dr. Barry Brooks and Dr. Sherron Helms have been added as Co-Investigators of the study

The committee requires that the protocol be reviewed at one of the regular IRB meetings within one year of its orginal approval date. We ask that you provide us with an update of your study at that time.

If there are any material changes in the investigation before the review, the committee requires notification.

The approval of the committee is based on your agreement not to initiate any changes in the approved research unless necessary to deal with an immediate hazard to a subject.

The committee requires that you report any unanticipated problems involving risk to human subjects or any noncompliance with the FDA Human Subject Regulations.

We wish you well with your worthy endeavors.

Sincerely,

EP Jenevein MD

Edwin P. Jenevein, M.D.
Chairman, Institutional Review Board
Texas Oncology, P.A.

3535 Worth Street, Suite 8037, Dallas, Texas 75246, (214) 820-8490, FAX (214) 820-8491

APPENDIX D

Graduate School Approval

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

THE GRADUATE SCHOOL
P.O. Box 22479
Denton, TX 76204-0479
Phone: 817/898-3400
Fax: 817/898-3412

March 7, 1996

Ms. Patricia VanMaanen
7721 Willow Stream Ct., #221
Dallas, TX 75230

Dear Ms. Van Maanen:

Thank you for providing the materials necessary for the final approval of your prospectus in the Graduate Office. I am pleased to approve the prospectus, and I look forward to seeing the results of your study.

If I can be of further assistance, please let me know.

Sincerely yours,

Leslie M Thompson

Leslie M. Thompson
Associate Vice President for
Research and Dean of the
Graduate School

dl

cc Dr. Susan Ward
Dr. William Cissell

APPENDIX E

Consent Form (February 8, 1996)

IRB# 96-03
2/8/96

APPROVED
FROM 2/13/96 TO 2/28/97

TEXAS ONCOLOGY, P.A. AND TEXAS WOMAN'S UNIVERSITY CONSENT TO PARTICIPATE IN A RESEARCH STUDY

STUDY TITLE:	First Time Chemotherapy Recipients' Knowledge Following Chemotherapy Education
PRINCIPAL INVESTIGATOR:	Patricia D. VanMaanen, RN, BSN, OCN
CO-INVESTIGATOR:	John Nemunaitis, M.D., Billie J. Marek, M.D., Ragene Rivera, M.D.
TELEPHONE NUMBER:	(214)229-7593 or (214)820-8700

BACKGROUND INFORMATION:

I understand that I have been asked to take part in a research study that will examine my understanding of the chemotherapy (drugs used to kill cancer) treatment I will be receiving following chemotherapy education.

The purpose of this research study is to determine the difference between the chemotherapy knowledge score obtained immediately following the chemotherapy education and prior to the third cycle of chemotherapy for first time chemotherapy patients.

I understand that this research study is being conducted by Patricia D. VanMaanen, RN, BSN, OCN as a thesis research project. This project is required to obtain a Master of Science from Texas Woman's University.

PROCEDURE (what will happen to me during the study):

I understand that if I agree to take part in this research study, I will be asked to complete a packet containing two questionnaires prior to my first treatment of chemotherapy. I will also complete a packet with two questionnaires prior to my third chemotherapy treatment. It will take approximately 15 minutes to complete each packet. The questions I am being asked to answer are about me, my chemotherapy treatment, and

the chemotherapy education I received. Approximately 50 patients will be asked to participate in this research study.

I understand that there will be no medicine or medical treatment with participation in this study.

I agree to give permission to the investigator(s) to review my medical record maintained by my oncologist to verify the accuracy of my responses to the questionnaires. My medical record will only be reviewed once and this will be after I complete the first packet.

RISK THAT MAY OCCUR DURING THE STUDY:

I understand that discussing my disease and its treatment may cause emotional distress.

BENEFITS FOR MY PARTICIPATION:

I understand that my participation in this research study will provide no direct medical benefit to me.

I understand that there is the possibility that my taking part in this research study will increase my awareness of chemotherapy. If I do not personally benefit, the knowledge learned from my participation may help in the development of better chemotherapy education for other patients in the future.

ALTERNATIVES TO PARTICIPATION:

I understand that my participation in this research study is strictly voluntary.

The following paragraphs contain the usual considerations involved in consenting to be a subject in a research study and are required by the Institutional Review Board for Human Protection of Texas Oncology, P.A. on all consent forms.

LIMITED LIABILITY OF THE INVESTIGATORS, TEXAS ONCOLOGY, P.A., AND TEXAS WOMAN'S UNIVERSITY:

The investigator(s) will make every effort to prevent physical injury that could result from this research. Compensation for physical injuries incurred as a result of participating in this research is not available from Texas Oncology, P.A., its affiliates, Texas Woman's University, nor the investigator(s). The investigators are prepared to advise me about medical treatment in case of adverse effects of these procedures, which I should report to him/her immediately at the telephone number already provided to me.
I understand that in the event of injury, illness, or adverse event resulting from this research study, no monetary compensation will be made. Financial compensation for lost wages, disability, discomfort due to this type of injury, illness, or adverse event is not available from Texas Oncology, P.A., its affiliates, the investigators, or Texas Woman's University. Medical care will be authorized by the attending physician. My acceptance of these conditions does not constitute a waiver of any rights I have under federal or state laws and regulations.

CONFIDENTIALITY:

I have a right to privacy, and all information that is obtained in connection with this study and that can be identified with me will remain confidential as possible within state and federal law. Everything the investigator(s) learn about me will be confidential. The results of this study may be published in a scientific journal or book, without identifying me by name. If the data is used for publication in the medical literature or for teaching purposes, names and other identifiers, such as photographs, audio or videotapes will be used only with my special written permission. I understand that I may see the photographs and videotapes and hear the audiotapes before giving this permission.

Records will be kept regarding my participation in the study and will be made available for review only as required by the Food and Drug Administration under the guidelines established by the Federal Privacy Act.

The information collected by the questionnaires will be studied. I understand that the Food and Drug Administration and the investigator(s) and/or the research nurse(s) are permitted to have access to my medical record and to data produced by the study, for audit purposes. However, they are required to maintain confidentiality.

The information collected by the questionnaires will be coded so name association with the information cannot occur. The names associated with the coded numbers will be stored separate from the questionnaires in a locked file cabinet and will be destroyed by a paper shredder after the data collection is complete. The completed questionnaires will be stored in a separate locked file cabinet. They, too, will be destroyed by a paper shredder after five years.

REQUEST FOR MORE INFORMATION:

I understand that if I have questions about the study or problems concerning my participation in the study, I should contact:

Patricia D. VanMaanen, RN, BSN, OCN at (214)229-7593 or .
Dr. John Nemunaitis, M.D. at (214)820-8700 or
The Office of Research & Grants Administration of Texas Woman's University at (817)898-3375

I understand that I will be informed of any significant new findings discovered in the course of this study which might influence my continued participation. Dr. Edwin P. Jenevein, Chairman of the Committee that reviews research on human subjects (Institutional Review Board at Texas Oncology, P.A.) will answer any questions about my rights as a research subject (214)879-3888.

REFUSAL OR WITHDRAWAL OF PARTICIPATION:

I understand that my participation is voluntary and that I may refuse to participate or may withdraw consent and discontinue participation in the study at any time without prejudice to my present or future care at Texas Oncology, P.A. Refusing to participate or withdrawing from this study will involve no penalty or loss of benefits to which I am otherwise entitled. I will be given a copy of this form to keep.

CERTIFICATION:

I have explained to _____ the purpose of the experimental study, the procedures required, and the possible risks and benefits to the best of my ability.

_____ _____/_____/_____
Signature of Investigator Date

I confirm that_____ has explained to me the purpose of the experimental study, the study procedures that I shall undergo, and possible risks and discomforts that I may experience. Alternatives to my participation in the study have also been discussed. I have read and understand this consent form. Therefore, I agree to give my consent to participate as a subject in this research study.

_____ _____/_____/_____
Signature of Subject Date

_____ _____/_____/_____
Signature of Witness Date

APPENDIX F

Consent Form (April 25, 1996)

IRB# 96-03
4/25/96

APPROVED FROM 5/6/96 TO 2/28/97

TEXAS ONCOLOGY, P.A. AND TEXAS WOMAN'S UNIVERSITY CONSENT TO PARTICIPATE IN A RESEARCH STUDY

STUDY TITLE:	First Time Chemotherapy Recipients' Knowledge Following Chemotherapy Education
PRINCIPAL INVESTIGATOR:	Patricia D. VanMaanen, RN, BSN, OCN
CO-INVESTIGATOR:	John Nemunaitis, M.D., Billie J. Marek, M.D., Ragene Rivera, M.D., Barry D. Brooks, M.D., Sherron R. Helms, M.D.
TELEPHONE NUMBER:	(214)229-7593 or (214)820-8700

BACKGROUND INFORMATION:

I understand that I have been asked to take part in a research study that will examine my understanding of the chemotherapy (drugs used to kill cancer) treatment I will be receiving following chemotherapy education.

The purpose of this research study is to determine the difference between the chemotherapy knowledge score obtained immediately following the chemotherapy education and prior to the third cycle of chemotherapy for first time chemotherapy patients.

I understand that this research study is being conducted by Patricia D. VanMaanen, RN, BSN, OCN as a thesis research project. This project is required to obtain a Master of Science from Texas Woman's University.

PROCEDURE (what will happen to me during the study):

I understand that if I agree to take part in this research study, I will be asked to complete a packet containing two questionnaires prior to my first treatment of chemotherapy. I will also complete a packet with two questionnaires prior to my third chemotherapy treatment. It will take approximately 15 minutes to complete each packet. The questions I am being asked to answer are about me, my chemotherapy treatment, and the

chemotherapy education I received. Approximately 50 patients will be asked to participate in this research study.

I understand that there will be no medicine or medical treatment with participation in this study.

I agree to give permission to the investigator(s) to review my medical record maintained by my oncologist to verify the accuracy of my responses to the questionnaires. My medical record will only be reviewed once and this will be after I complete the first packet.

RISK THAT MAY OCCUR DURING THE STUDY:

I understand that discussing my disease and its treatment may cause emotional distress.

BENEFITS FOR MY PARTICIPATION:

I understand that my participation in this research study will provide no direct medical benefit to me.

I understand that there is the possibility that my taking part in this research study will increase my awareness of chemotherapy. If I do not personally benefit, the knowledge learned from my participation may help in the development of better chemotherapy education for other patients in the future.

ALTERNATIVES TO PARTICIPATION:

I understand that my participation in this research study is strictly voluntary.

The following paragraphs contain the usual considerations involved in consenting to be a subject in a research study and are required by the Institutional Review Board for Human Protection of Texas Oncology, P.A. on all consent forms.

LIMITED LIABILITY OF THE INVESTIGATORS, TEXAS ONCOLOGY, P.A., AND TEXAS WOMAN'S UNIVERSITY:

The investigator(s) will make every effort to prevent physical injury that could result from this research. Compensation for physical injuries incurred as a result of participating in this research is not available from Texas Oncology, P.A., its affiliates, Texas Woman's University, nor the investigator(s). The investigators are prepared to advise me about medical treatment in case of adverse effects of these procedures, which I should report to him/her immediately at the telephone number already provided to me.

I understand that in the event of injury, illness, or adverse event resulting from this research study, no monetary compensation will be made. Financial compensation for lost wages, disability, discomfort due to this type of injury, illness, or adverse event is not available from Texas Oncology, P.A., its affiliates, the investigators, or Texas Woman's University. Medical care will be authorized by the attending physician. My acceptance of these conditions does not constitute a waiver of any rights I have under federal or state laws and regulations.

CONFIDENTIALITY:

I have a right to privacy, and all information that is obtained in connection with this study and that can be identified with me will remain confidential as possible within state and federal law. Everything the investigator(s) learn about me will be confidential. The results of this study may be published in a scientific journal or book, without identifying me by name. If the data is used for publication in the medical literature or for teaching purposes, names and other identifiers, such as photographs, audio or videotapes will be used only with my special written permission. I understand that I may see the photographs and videotapes and hear the audiotapes before giving this permission.

Records will be kept regarding my participation in the study and will be made available for review only as required by the Food and Drug Administration under the guidelines established by the Federal Privacy Act.

The information collected by the questionnaires will be studied. I understand that the Food and Drug Administration and the investigator(s) and/or the research nurse(s) are permitted to have access to my medical record and to data produced by the study, for audit purposes. However, they are required to maintain confidentiality.

The information collected by the questionnaires will be coded so name association with the information cannot occur. The names associated with the coded numbers will be stored separate from the questionnaires in a locked file cabinet and will be destroyed by a paper shredder after the data collection is complete. The completed questionnaires will be stored in a separate locked file cabinet. They, too, will be destroyed by a paper shredder after five years.

REQUEST FOR MORE INFORMATION:

I understand that if I have questions about the study or problems concerning my participation in the study, I should contact:

> Patricia D. VanMaanen, RN, BSN, OCN at (214)229-7593 or Dr. John Nemunaitis, M.D. at (214)820-8700 or The Office of Research & Grants Administration of Texas Woman's University at (817)898-3375

I understand that I will be informed of any significant new findings discovered in the course of this study which might influence my continued participation. Dr. Edwin P. Jenevein, Chairman of the Committee that reviews research on human subjects (Institutional Review Board at Texas Oncology, P.A.) will answer any questions about my rights as a research subject (214)879-3888.

REFUSAL OR WITHDRAWAL OF PARTICIPATION:

I understand that my participation is voluntary and that I may refuse to participate or may withdraw consent and discontinue participation in the study at any time without prejudice to my present or future care at Texas Oncology, P.A. Refusing to participate or withdrawing from this study will involve no penalty or loss of benefits to which I am otherwise entitled. I will be given a copy of this form to keep.

IRB# 96-03
4/25/96

CERTIFICATION:

I have explained to_____the purpose of the experimental study, the procedures required, and the possible risks and benefits to the best of my ability.

_____ _____/_____/_____

Signature of Investigator Date

I confirm that_____has explained to me the purpose of the experimental study, the study procedures that I shall undergo, and possible risks and discomforts that I may experience. Alternatives to my participation in the study have also been discussed. I have read and understand this consent form. Therefore, I agree to give my consent to participate as a subject in this research study.

_____ _____/_____/_____

Signature of Subject Date

_____ _____/_____/_____

Signature of Witness Date

APPENDIX G

Chemotherapy Knowledge Questionnaire

Part I

code#_____
date_____

CHEMOTHERAPY KNOWLEDGE QUESTIONNAIRE

PART I (Completed by the researcher from medical record)

1. Site of treatment_____

2. Has there been a change in chemotherapeutic agents since first interview? (for administration #2 only)_____
_____

3. Diagnosis:_____

4. Name of chemotherapy agents_____
_____

5. Purpose of treatment: (circle one) cure control

APPENDIX H

Chemotherapy Knowledge Questionnaire

Part II

code#_____
date_____

CHEMOTHERAPY KNOWLEDGE QUESTIONNAIRE

Part II

1. I would like to know the purpose for your chemotherapy treatment.

	YES	NO
To cure the cancer	_____	_____
To control the cancer (not cure)	_____	_____
Unsure	_____	_____

2. Here is a list of drugs commonly given to cancer patients. The names in the parentheses are other names the drug can be called. I would like to know which drugs, if any, you are taking. Please indicate which drugs you are taking by placing a check mark in front of the drug's name on the list.

_____ Adriamycin (Doxorubicin)
_____ Asparaginase
_____ BCNU (Carmustine)
_____ Bleomycin (Blenoxane)
_____ Busulfan (Myleran)
_____ Carboplatin (Carboplat)
_____ CCNU (Lomustine)
_____ Chlorambucil (Leukeran)
_____ CIS Platin (Platinin) (Platinol)
_____ Cladribine (Leustatin)

code#_____
date_____

2. (continued)

_____ Cytarabine (Ara-C) (Cytosar)

_____ Cytoxan (Cyclophosphamide)

_____ DTIC (Dacarbazine)

_____ Etoposide (VP-16)

_____ Floxuridine (FUDR)

_____ Fludara (Fludarabine)

_____ Fluorouracil (5-FU)

_____ Hexamethylmelamine

_____ Hydroxyurea (Hydrea)

_____ Interferon (Roferon) (Welferon) (Intron A)

_____ Interleukin (IL2) (Aldesleukin)

_____ Levamisole

_____ Melphalan (Alkeran)

_____ Methotrexate (Amethopterin)

_____ Mithramycin (Mithracin) (Plicamycin)

_____ Mitomycin-C (Mutamycin)

_____ Navelbine (Vinorelbine)

_____ Nitrogen Mustard (Mustargen)
(Mechlorethamine)

_____ Novantrone (Mitoxantrone)

_____ Procarbazine (Matulane)

_____ Taxol (Paclitaxel)

_____ Vinblastine (Velban)

_____ Vincristine (Oncovin)

_____ VM-26 (Teniposide)

_____ Other(specify)_____

code#_____
date_____

3. From the chemotherapy education your physician or nurse has given you, you have learned that sometimes people experience side effects when taking this (these) drug(s). On the next pages you will find a list of side effects that sometimes occur with some chemotherapy drugs. Which of these side effects, if any, have you learned might commonly occur with your chemotherapy. Place a check mark by those that apply.

_____ Anemia

_____ Bleeding

_____ Infection

_____ Low blood count (low white cell count, low red blood cell count, low platelet count)

_____ Fever/chills

_____ Fatigue

_____ Flu-like syndrome

_____ Headache

_____ Muscle weakness

_____ Muscle pain/joint pain

_____ Nasal congestion

_____ Pain--generalized pain or pain in the area of your tumor

_____ Pain--along the vein during or after receiving your chemotherapy

_____ Pain--abdominal

_____ Increased coloring of skin under the nails or along the veins (hyperpigmentation)

code#_____
date_____

3. (continued)

_____ Appetite--decreased (anorexia)
_____ Constipation
_____ Diarrhea
_____ Liver damage--liver toxicity
_____ Mouth sores (stomatitis)
_____ Nausea and Vomiting
_____ Taste and smell changes
_____ Blood in urine (hematuria) or painful urination (dysuria)
_____ Red colored urine
_____ Kidney damage--renal toxicity
_____ Urinary retention--unable to urinate all the urine that is in the bladder
_____ High blood pressure (hypertension)
_____ Lower blood pressure (hypotension)
_____ Heart damage--cardiac toxicity
_____ Shortness of breathe--dyspnea
_____ Thinning of hair or baldness
_____ Skin sensitive to sunlight
_____ Skin--ulcer (sore) formation if drug is accidentally given into the tissue instead of the vein during administration of the drug (extravasation)
_____ Skin--redness and peeling (sloughing)
_____ Skin--changes in areas that have been previously treated with radiation therapy
_____ Skin--rash, itching, peeling, hives (dermatitis)

code#_____
date_____

3. (continued)

_____ Numbness--tingling in hands and feet (peripheral neuropathies)

_____ Ringing sensation in your ears (tinnitis) or hearing loss

_____ Mood changes

_____ Confusion

_____ Nervousness, irritability, insomnia (difficulty sleeping)

_____ Menstrual irregularities

_____ Sterility

4. Next you will find the same list of side effects that sometimes occur with chemotherapy drugs. Many of these side effects may not be due to your chemotherapy drugs. Which of these side effects, if any, have **you actually experienced** since you began your chemotherapy treatments? Place a check mark by only those side effects you have experienced.

_____ Anemia

_____ Bleeding

_____ Infection

code#_____
date_____

4. (continued)

_____ Low blood count (low white cell count, low red blood cell count, low platelet count)

_____ Fever/chills

_____ Fatigue

_____ Flu-like syndrome

_____ Headache

_____ Muscle weakness

_____ Muscle pain/joint pain

_____ Nasal congestion

_____ Pain--generalized pain or pain in the area of your tumor

_____ Pain--along the vein during or after receiving your chemotherapy

_____ Pain--abdominal

_____ Increased coloring of skin under the nails or along the veins (hyperpigmentation)

_____ Appetite--decreased (anorexia)

_____ Constipation

_____ Diarrhea

_____ Liver damage--liver toxicity

_____ Mouth sores (stomatitis)

_____ Nausea and Vomiting

_____ Taste and smell changes

_____ Blood in urine (hematuria) or painful urination (dysuria)

code#_____
date_____

4. (continued)

_____ Red colored urine

_____ Kidney damage--renal toxicity

_____ Urinary retention--unable to urinate all the urine that is in the bladder

_____ High blood pressure (hypertension)

_____ Lower blood pressure (hypotension)

_____ Heart damage--cardiac toxicity

_____ Shortness of breathe--dyspnea

_____ Thinning of hair or baldness

_____ Skin sensitive to sunlight

_____ Skin--ulcer (sore) formation if drug is accidentally given into the tissue instead of the vein during administration of the drug (extravasation)

_____ Skin--redness and peeling (sloughing)

_____ Skin--changes in areas that have been previously treated with radiation therapy

_____ Skin--rash, itching, peeling, hives (dermatitis)

_____ Numbness--tingling in hands and feet (peripheral neuropathies)

_____ Ringing sensation in your ears (tinnitis) or hearing loss

_____ Mood changes

_____ Confusion

_____ Nervousness, irritability, insomnia (difficulty sleeping)

code#_____
date_____

4. (continued)

_____ Menstrual irregularities

_____ Sterility

APPENDIX I

Demographic Inventory I

code#_____

DEMOGRAPHIC INVENTORY I

1. Your age: _____

2. Female_____ Male_____ (choose one)

3. Have you ever received chemotherapy or radiation therapy before? (choose one)

   Yes_____
   No _____

4. Circle the highest grade or year you completed in school.

Grade School								High School				College				Graduate School						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	>22

5. Did you receive written educational information about the chemotherapy treatment you will receive? (choose one)

   Yes_____
   No _____

6. Did you receive verbal educational information about the chemotherapy treatment you will receive? (choose one)

   Yes_____
   No _____

7. Were you able to read the written educational information you received? (choose one)

   Yes_____
   No _____
   Information not received_____

DEM#1/10-95

code#_____

8. Were you able to understand the written educational information you received? (choose one)

Yes_____
No _____
Information not received_____

9. Were you able to understand the verbal educational information you received? (choose one)

Yes_____
No_____
Information not received_____

10. Was the educational information you received new information for you? (choose one)

Yes_____
No _____

11. How would you rate the usefulness of the written educational information you received about your chemotherapy treatment: (choose one)

not useful _____
useful _____
very useful _____

12. How would you rate the usefulness of the verbal educational information you received about your chemotherapy treatment: (choose one)

not useful _____
useful _____
very useful _____

13. What could have been done differently if anything, to improve the educational information you received about your chemotherapy treatment?

_____

_____

_____

APPENDIX J

Demographic Inventory II

code #_____

DEMOGRAPHIC INVENTORY II

1. Will you be receiving your third course of chemotherapy today? (check one)

   Yes_____
   No _____

2. How many times did you call your oncologist (the doctor who is treating your cancer) or the oncologist's office since you began your chemotherapy treatments: (circle the one best answer)

   A. I have not called my oncologist
   B. 1 to 4 phone calls
   C. 5 to 8 phone calls
   D. 9 or more phone calls

3. What was the most common reason to call your oncologist: (circle the one best answer)

   A. Not applicable, I did not call my oncologist
   B. Appointment information or changes
   C. Laboratory information or results
   D. Side effect management (i.e., nausea, fevers, other difficulties, etc.)
   E. Other (specify)_____

4. When calling your oncologist who did you most often speak with directly, to answer your question? (circle the one best answer)

   A. The Oncologist
   B. The oncologist's nurse
   C. The infusion room nurse (the nurse who administers the chemotherapy)
   D. The appointment secretary

APPENDIX K

Permission to Use

The Chemotherapy Knowledge Questionnaire

Date: September 20, 1995

I, Marylin J. Dodd, RN, PhD, FAAN, give Patricia VanMaanen RN, BSN, OCN, consent to use the Chemotherapy Knowledge Questionnaire developed by me in 1981 in her graduate thesis research project. I also give Patricia VanMaanen RN, BSN, OCN, permission to modify the Chemotherapy Knowledge Questionnaire (i.e., omit question(s), etc.) if she so desires for the purpose of using the questionnaire in her graduate thesis research project.

(print name)

Marylin J Dodd
signature

Sept 20/95
date

APPENDIX L

Cover Letter Packet 1

March 4, 1996

Dear New Chemotherapy Patient:

The study that you have been asked to participate in will be looking at what you know about chemotherapy after you have been told about your treatment.

Your participation in the study is strictly voluntary. It asks you to answer two sets of questionnaires at two different times. Before your first treatment you will answer one set. Before your third chemotherapy treatment you will answer the second set.

The envelope given to you by the nurse today contains the first set of questionnaires. One asks information about you that will be helpful in the study. It is called the Demographic Inventory I. The other questionnaire will ask you questions about your chemotherapy treatment. It is called the Chemotherapy Knowledge Questionnaire. The questionnaires will take about 15 minutes to finish.

Directions For Answering The Questionnaires:

1. The Demographic Inventory I: Read each question carefully. Some questions ask you to write in your answer. Other questions ask you to circle one answer. You will answer 13 questions in this section.

2. The Chemotherapy Knowledge Questionnaire: Please read each question carefully. A check mark next to the answer you select will answer these questions. You will answer 3 questions in this section.

3. When you have finished answering the questionnaires put them back in the envelope and seal the envelope. Please return the envelope to the nurse.

Thank you for your help with this study,

Patricia D. VanMaanen, RN, BSN, OCN
Graduate Student, Texas Woman's University

APPENDIX M

Cover Letter Packet #2

April 15, 1996

Dear Chemotherapy Patient:

I would like to thank you for participating in this study. As you may recall, the study is looking at what you know about your chemotherapy treatment. It is time to complete the second and final questionnaire packet for this study.

This envelope contains two questionnaires. The first questionnaire asks information about you that will be helpful in the study. It is called the Demographic Inventory II. The other questionnaire is the Chemotherapy Knowledge Questionnaire. It will ask you about your chemotherapy treatment. The questionnaires will take about 15 minutes to complete.

Your participation in this study remains strictly voluntary. Your name will not be reported with the results of this study. If you decide to withdrawal for the study you will not be penalized in any way.

I will be happy to answer any questions about the study. I can be reached at (214)229-7593. You may also contact the Office of Research & Grants Administration at Texas Woman's University at (817)898-3375 or Dr. John Nemunaitis at (214)820-8700 with any questions.

Directions For Answering The Questionnaires:

1. The Demographic Inventory II. Please read each question carefully. Some questions ask you to write in your answer. Other questions ask you to circle one answer. You will answer 4 questions in this section.

2. The Chemotherapy Knowledge Questionnaire. Please read each question carefully. A check mark next to the answer you pick will answer these questions. You will answer 4 questions in this section.

3. When you have finished answering the questionnaires put them back in the envelope and seal the envelope. Please return the envelope to the nurse.

Thank you for your continued help in this research study,

Patricia D. VanMaanen, RN, BSN, OCN
Graduate Student, Texas Woman's University