

1991

Cancer Patients' Response to Chemotherapy Teaching on Side Effect Management

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CANCER PATIENTS' RESPONSE TO CHEMOTHERAPY
TEACHING ON SIDE EFFECT MANAGEMENT

BY

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A THESIS

Submitted to
Grand Valley State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE IN NURSING

Kirkhof School of Nursing

1991

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ABSTRACT

Cancer Patients' Response to Chemotherapy

Teaching on Side Effect Management

by

Kelly A. Guswiler

The purpose of this descriptive study was to investigate patients' responses to chemotherapy teaching on drug side effects and side effect management. Concepts of self-care from Orem's theory of Self-Care Deficits provided the conceptual framework.

Nineteen cancer patients were given specific information on chemotherapy side effects and side effect management prior to initiating treatment. Patients maintained a written log of experienced side effects and self-care behaviors that they initiated to manage these effects. Number of side effects, intensity and distress rating of side effects, reported self-care behaviors, and effectiveness of the behaviors were analyzed using percentages. Nausea/vomiting, diarrhea, stomatitis, and alopecia were cited as the most frequently experienced side effects. The most frequently performed self-care behaviors were taking prescribed medication, diet selection, oral care, and wearing a wig. Teaching information sheets were the most frequent source of information used to manage chemotherapy side effects.

I dedicate this work to my husband, Brian, who has supported me throughout my educational endeavor and to my new baby, Brandon, who is the joy of my life.

Acknowledgements

The investigator wishes to express her appreciation to Dr. Emily Droste-Bielak, Dr. Patricia Underwood, and Ruth Ann Brintnall, for their guidance, assistance and countless hours of dedication in assisting me with this thesis. Sincere thanks is also extended to oncology nurses: Lora Angellotti, Leone Powell, and Linda Watt, who assisted me with data collection.

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CHAPTER 1

INTRODUCTION

Cancer and its treatment represent significant challenges for the health care system in America. Chemotherapy, in particular, presents a challenge for patients, families, and health care professionals. In 1986, approximately 557,000 cancer patients were treated with systemic chemotherapy (Devita, 1989). More patients are receiving chemotherapy in outpatient treatment facilities than ever before, because it is cost effective and convenient for the patient. Patients are treated with a chemotherapy regimen over a period of hours in an outpatient clinic or physician's office and are released. If a patient is going to experience side effects from treatment, they will most likely experience these effects at home.

Although some side effects of chemotherapy drugs such as nausea can occur within minutes to days after the drugs are given, a potentially life threatening side effect such as myelosuppression can occur from one to four weeks. The most dangerous side effects that the patient will usually encounter occur after the patient has left the treatment facility. Patients and families need to become

more familiar with their disease, treatment regimens, and side effects. If they receive their treatments in an outpatient clinic or office, they must be provided with specific information on how to self-manage treatment side effects.

Chemotherapy teaching has focused on educating patients about the drugs they are receiving and what side effects they may experience (Dodd & Mood, 1981). Oncology nurses need to expand this teaching to include information on self-care management of side effects.

Problem Statement

Cancer patients receiving chemotherapy need information about the drugs they take and the self-care they must practice in order to help prevent serious complications. "For the self-care behaviors to be effective, cancer patients are required to know the range of side effects they are likely to experience; they also need precise instruction on how to manage the side effects" (Dodd, 1983, p. 63). The nurse's responsibility is to assess these patients and determine their educational needs regarding drugs, potential side effects and appropriate self-care measures. Once patients gain adequate knowledge about their drugs and self-care measures, they should be able to distinguish when they can manage their side effects at home or when they should seek medical attention. The self-care behaviors studied in this investigation included patients' ability to identify which side effects occurred after they received chemotherapy

and what self-care behaviors they performed once the side effects occurred.

Purpose

The purpose of this study was to gain knowledge of effective teaching methods utilized by oncology nurses. This study evaluated patient responses to chemotherapy teaching which included information on drug side effects and side effect management. Ultimately, information obtained from this study can be used to improve the health care management of oncology patients and to promote self-care management and well being.

CHAPTER 2

REVIEW OF LITERATURE AND CONCEPTUAL FRAMEWORK

Review of Literature

The literature review for this study outlined nursing research which evaluated the effectiveness of patient education. The first section identifies what research has been documented in regard to patient education in various patient populations and the second section outlines research which specifically addressed the issue of self-care management by oncology patients.

In the past few decades, research has been conducted on the benefits of patient education. Most of the studies which focused on patient education examined the effect of structured versus unstructured instruction in the areas of diabetes management (Etzwiler, 1986; Terent, Hagfall, & Cederholm, 1985), cardiac rehabilitation (Linde & Janz, 1985), and pre/post operative surgery teaching (Hathaway, 1986; Marshall, Penckofer, & Llewellyn, 1986). Only a few studies (Derdiarian, 1987; Dodd & Mood, 1981; Fernsler, 1985; Graham & Schubert, 1985; Johnson, 1982; and Morrow, Gootnick, & Schmale, 1977) examined patient education in the population of cancer patients. Growing evidence demonstrates that education can improve knowledge, attitude,

behavior, and health status of the cancer patient (Rimer, Keintz, & Glassman, 1985).

Recently, nurse researchers have studied the importance of teaching self-care management to patients and families. Most of this research has been focused in the areas of diabetes management (Graham & Schubert, 1984), cardiac rehabilitation (Marshall, Penckofer, & Llewellyn, 1986), and surgery (Williams et al., 1986). A few studies have investigated the importance of teaching self-care behaviors to patients who have cancer and are receiving chemotherapy. Dodd & Mood (1981) and Dodd (1982a, 1982b, 1983, 1984a, 1984b, 1987, 1988a, and 1988b) performed a series of research studies which addressed different factors in cancer patient education. The results from the initial studies indicated that cancer patients lacked knowledge of chemotherapy drugs and side effects. The later studies revealed that cancer patients performed few self-care behaviors to manage their side effects.

Dodd and Mood's (1981) initial study was conducted to assess the cancer patient's level of knowledge. Thirty patients involved in phase I or II clinical trials of experimental chemotherapeutic agents received a standard informed consent form which outlined the chemotherapy drug side effects. At the time of obtaining informed consent, patients were given a questionnaire to assess knowledge of the drugs they were receiving, possible side effects of the drugs, and the purpose for receiving chemotherapy.

This descriptive study sought to determine how much information was retained after informed consent was given. The results of the study indicated that 70% of the subjects could not identify the drugs they were receiving. Also, subjects could only identify an average of 3.56 potential side effects out of an average of 11.86 possible side effects. Only 10(33%) of the subjects could identify the lethal side effects of infection and bleeding.

In a second study (Dodd and Mood, 1981), twenty-four subjects were randomly placed into an experimental or control group. All subjects received a visit from a nurse within 48-72 hours after they had given informed consent for chemotherapy. The subjects in the experimental group reviewed information about their chemotherapy drug(s) and their potential side effects. Each subject also received an index card with the same written information which they could keep. The subjects in the control group received a visit by the same nurse but they did not receive a review of information about the side effects of their drugs. Instead, the subjects were given information about their disease.

Three to four weeks after the nurse's visit, the subjects' knowledge of chemotherapeutic agents and side effects was evaluated. The experimental group recalled significantly more names of drugs they were receiving ($t(22)=2.72$, $p<0.05$) than the control group. This group could also recall significantly more of their drug's possible side effects ($t(22)=3.21$, $p<0.01$), of possible

lethal side effects ($t(22)=4.75$, $p<0.01$), and the purposes for receiving chemotherapy ($t(22)=2.22$, $p<0.05$). There was no difference between the groups in the number of incorrectly identified potential side effects. The accuracy of recognition of the potential lethal side effects was the most pronounced difference between the two groups with an accuracy rate of 71% for the experimental group and 21% for the control group.

Dodd (1982b, 1983) continued to study patients' knowledge of chemotherapy and side effects but also became interested in whether patients could identify self-care behaviors needed to manage side effects that may occur once the patients were away from the treatment facility. This study was conducted in two parts. In part I, Dodd (1982b) reported the patterns of self-care activity of patients receiving chemotherapy prior to receiving information interventions. In part II, Dodd (1983) studied the effectiveness of the intervention.

In part I, Dodd (1982b) studied 48 cancer patients with varying diagnoses and chemotherapy treatment regimens. Patients were recruited through the Visiting Nurses Association and a group of privately practicing oncologists. Each patient was interviewed by the researcher and given a questionnaire to fill out. This Chemotherapy Knowledge and Self-Care Behavior questionnaire asked patients to identify the side effects they were experiencing from a list of 44 side effects, how severe these side effects were, and what

action had been taken to alleviate the side effects. The results of the study indicated that patients reported experiencing an average of 7.69 side effects but initiating only an average of 0.81 self-care behaviors. From this research, Dodd concluded that "the discrepancy between experienced side effects and initiated self-care behavior was attributed to lack of information from the physicians and nurses and the patients' limited knowledge of self-care measures" (Dodd, 1982b, p. 447).

In part II, Dodd (1983) randomly assigned the same 48 patients to one of four groups. Group one received drug information only; the second group received information on side effect management techniques (SEMT); the third group received combined drug and SEMT; and the fourth group was the control. Patients in all four groups were interviewed privately by the investigator. Four to nine weeks later, subjects were re-interviewed by data collectors who did not know to which group a patient was assigned.

Patients who received SEMT, with or without drug information, scored higher on self-care performance than patients who did not receive any SEMT. The mean self-care performance of patients who received combined information on drugs and SEMT was significantly higher than those who received SEMT alone ($f(1,44) = 7.60, p < 0.01$). In addition, there was a significant positive relationship between severity of side effects and initiation of self-care ($r = 0.38, p = 0.007$). After intervention, no such relationship

was observed for patients who received SEMT information ($r=0.19$, $p=0.36$). The relationship however, continued to be statistically significant for patients who did not receive SEMT information ($r=0.41$, $p=0.04$). SEMT patients initiated self-care behaviors before their side effects became severe.

The results of Dodd's studies (1982b, 1983) indicated that patients who received specific information on how to deal with their side effects reported initiating more self-care behaviors than those who did not receive specific information. The patients who were given specific information on how to deal with their side effects were able to initiate self-care behaviors sooner and prevent side effects from progressing to life threatening situations.

Dodd (1984a) continued to pursue research in the area of self-care behavior of cancer patients and expanded her population of interest to patients who were receiving radiation therapy. A descriptive study of 30 cancer patients was initiated to determine self-care behaviors for the management of radiation therapy side effects. Patients recorded their self-care actions in a self-care behavior log during a four to seven week period. The findings of this study were similar to the earlier studies with chemotherapy patients. Radiation therapy patients reported experiencing an average of 3.3 side effects and initiating few ($M=1.6$, $SD=.80$) self-care activities.

Later, Dodd (1987a) conducted an experimental study with patients who were given specific side effect management

information on how to manage side effects of radiation therapy. Sixty patients were randomly assigned to an experimental or control group. Thirty subjects assigned to the experimental group were given side effect management techniques (SEMT) and all patients, including the thirty subjects in the control group, were given standard suggestions on how to manage radiation therapy side effects. Patients who received SEMT information scored an average of 1.0 on the selected SCB ratio. The mean score of patients who did not receive SEMT information was 0.66. These differences were statistically significant: ($t(58)=2.4$, $p=0.02$).

On the other hand, patients who did receive SEMT information delayed initiating self-care behaviors an average of 0.6 day ($SD=1.2$) in comparison with an average delay of 1.2 days ($SD=2$) for the control group. One reason for these results may be that the emphasis of SEMT information was on how to manage experienced side effects, not how to prevent their occurrence. Radiation therapy patients generally do not experience significant side effects until the treatment regimen is almost completed. There is some evidence from previous self-care studies (Dodd, 1983, 1984) that patients are not inclined toward preventive activity; they wait until the side effects are experienced before initiating self-care.

Dodd (1988b), repeated the study with patients who were receiving chemotherapy. In this experimental study,

patients were given side effect management information on all side effects of chemotherapy that they were likely to develop. Sixty patients beginning chemotherapy were randomly assigned to an experimental or control group. They recorded their experienced side effects in a Self-Care Behavior Log. The patients who received proactive information on side effect management scored significantly higher on all of the self-care behavior (SCB) ratios and preventive measures than the control group (selected SCB ratio $\underline{M}=1.3$ $\underline{t}(58)=2.50$, $p=.015$; total SCB ratio $\underline{M}=1.81$, $\underline{t}(58)=2.18$, $p=.03$; SCB efficacy ratio $\underline{M}=3.16$, $\underline{t}(58)=2.33$, $p=.02$; SCB overall management ratio $\underline{M}=3.13$, $\underline{t}(58)=2.19$, $p=.03$). Receiving information on side effect management information did not significantly reduce the delay in initiating self-care behaviors in the control group. Also, the patients who received side effect management information performed significantly more preventive self-care activities ($\underline{M}=2.03$, $SD=1.8$) than the control group patients ($\underline{M}=0.87$, $SD=1.6$, $\underline{t}(58)=2.6$, $p<.01$).

A threat to the external validity of Dodd and Mood's (1981) study is related to the sample. Education and employment were not equally distributed. Only 3 of the 30 subjects admitted to the study were employed in professional occupations and the mean educational level of the group was 9.5 years. The lower educational level of the subjects may reflect an inability to understand the teaching intervention and to identify drug names and side effects. In Dodd's

(1984b and 1988) later works, she used Hollingshead's two-factor index of social position in order to control for this factor. This index utilizes the factors of education and occupation to determine social position on a 5-point scale, with 1 being the highest social position.

A threat to internal validity existed in Dodd's initial studies (Dodd & Mood, 1981; Dodd, 1982b, 1983, 1984a). A period of four to nine weeks elapsed between the time of the teaching intervention. Because of this time lapse, it is difficult to determine the source of the patients' knowledge. The patients may have learned more information from the nurse's visit or they could have picked-up information from other sources such as family, friends or literature. Dodd (1984) later developed a Self-Care Behavior Log which required the patient to write down side effects as they occurred, actions taken to lessen or prevent side effects, and identify the source of information.

Another threat to internal validity occurred once the Self-Care Behavior log was utilized in later studies (Dodd, 1984a, 1987, 1988). This threat was in the instrumentation. Patients were asked to write down any side effects that they experienced and then write the self-care behaviors that they initiated to relieve those side effects. It would be unlikely for patients to write down experienced side effects and not do any thing to relieve it. This may be a reason why the experimental groups usually scored higher on self-care behavior ratios than the control groups.

Dodd's research over the years has provided insight into the educational needs of patients who are receiving chemotherapy. It has given nurses a valid reason for teaching chemotherapy side effects management. It is difficult to generalize results from these studies to all chemotherapy patients because of the small sample sizes. Similar results have been found in studies which examined informed consent for radiation therapy (Morrow, Gootneck, & Schmale 1978) and for patients undergoing chemotherapy for breast cancer (Muss et al., 1979). Dodd's, research has provided direction for chemotherapy education and laid the ground work for future studies.

In summary, the evolution of nursing research on patient education focused on the educational deficits of surgical and diabetic patients. From these studies, nurses found that patient education can minimize treatment side effects and complications and enhance the patient's ability to engage in self-care behaviors. Only in the last decade has research been expanded to address patient education for oncology patients.

Conceptual Framework

Orem's theory of self-care is based on the assumption that all persons require self-care in some manner in order to maintain an optimal level of health and well being. Self-care agency refers to "capabilities of individuals to perform actions to take of themselves and others" (Orem, 1991, p.145). In relation to oncology patients receiving

outpatient chemotherapy treatments, side effect management is the self-care process that patients perform in order to maintain well being.

Therapeutic self-care demand is the amount of care that a patient requires over time to meet existing requisites to maintain life or promote health, development, and general well being. For oncology patients, these measures of care may be numerous due to the complexity of the disease and treatment.

Self-care agency is the ability of an individual to engage in actions essential for self-care. A self-care deficit occurs when there is a difference between self-care agency and therapeutic self-care demand and the self-care agency is not able to meet the known therapeutic self-care demand. A self-care deficit that may exist for an oncology patient who is receiving chemotherapy is lack the knowledge of how to perform self-care behaviors. Provision of information about chemotherapy side effects and side effect management increases the self-care agency. Generally, an increase in self-care agency results in more self-care behaviors.

The central idea of the self-care deficit theory is that "people can benefit from nursing because they are subject to health-related or health-derived limitations that render them incapable of continuous self-care or dependent care or that result in ineffective or incomplete care" (Orem, 1985, p.34). Self-care deficits occur when

individuals are no longer able to completely care for themselves. Self-care deficits may also arise from the individual's inability to engage in self-care because of limitations of age, developmental state, life experience, sociocultural orientation, health and available resources. Nurses caring for oncology patients need to make a thorough assessment of the patients' demographic background in order to accurately assess their deficits and develop a plan of care that will address the patient's self-care needs.

Cancer patients receiving chemotherapy may experience a health-deviation self-care requisites due to their lack of knowledge of chemotherapy side effects. Health deviation self-care requisites occur when a change in the health status alters the patients' ability to meet their self-care demands. Patients need information about their chemotherapy treatments to know what possible side effects they may experience and learn how to care for themselves if side effects occur or how to prevent further complications. By earlier identification of side effects, patients can take measures that would prevent the side effects from progressing into a possible life threatening situation, thus interfering with their universal self-care requisites.

Orem's theory of self-care is testable and has been used widely within nursing practice of direct patient care, research, and curriculum development. The theory of self-care is applicable as a basis for oncology nursing because it directs the educational practice of teaching the oncology

patients to care for themselves. Dodd (1982, 1983, 1984, 1987, and 1988) and Fernsler (1885) documented using Orem's theory of self-care in their conceptual framework for their research on self-care with oncology patients.

The limitation of Orem's theory of self-care is in her definition of health. She defines health as "a description of living things with respect to their structural and functional wholeness and soundness" (Orem 1991, p. 362). This lends one to believe that the patient must be fully functioning to be considered healthy. An oncology patient may not be considered healthy by Orem's definition, yet be able to perform self-care measures and operate at an optimal level of wellness.

Summary and Implications for the Study

More cancer patients are receiving chemotherapy in physician's offices or outpatient clinics than ever before. The side effects that patients may experience associated with their treatment regimen may occur two hours to several weeks after they have received their treatment. This results in more patients experiencing side effects while at home and not under the immediate supervision of health professionals. It is our responsibility as nurses to improve our teaching methods to promote self-care management. Chemotherapy teaching should include information on: drugs, potential side effects, and most importantly, self-care behaviors that can be initiated to minimize or prevent side effects. By providing chemotherapy

education, oncology nurses can enhance patients' ability to manage chemotherapy side effects and ultimately improve their quality of life.

Research Questions

1. What side effects are reported by persons receiving chemotherapy?
2. How do patients rate the intensity of experienced side effects?
3. How do patients rate the distress of experienced side effects?
4. What self-care behaviors (actions) do patients initiate to alleviate or lessen the side effect of chemotherapy treatment?
5. How do patients rate the effectiveness of each self-care behavior?
6. What was the most frequently identified source of information cited for the actions taken to manage the experienced side effects?

Definition of Terms

Self-care behaviors: behaviors that the patient initiates in response to the side effects that are experienced secondary to chemotherapy treatment. These behaviors are defined as being positive behaviors that the patient performs in order to prevent or minimize the side effects. These behaviors may be expressed in the form of specific physical

actions or the process of notifying a health care professional of the symptoms (Dodd, 1987b).

Side effect management teaching: provision of specific information regarding chemotherapy side effects (Appendix A) and how to manage these side effects (Dodd, 1987b).

Experienced side effect: physiological or emotional effects that a patient experiences after receiving chemotherapy which are directly related to the chemotherapeutic agent received (Appendix B).

Chemotherapy treatment cycle: treatment which consists of receiving oral and/or intravenous cytotoxic drugs on specific days during a period of three to six weeks.

Appropriate side effect management: those self-care actions which are identified by the subjects in the side effect management sheets and in nursing literature (Dodd, 1987b).

Perceived intensity: the patient's perception of intensity of the side effect rated on a scale of one to five with one being barely noticeable and five being most severe (Appendix B).

Perceived distress: patient's perception of the distress of the side effect rated on a scale of one to five. One is a minor annoyance and five is extremely distressing (Appendix B).

CHAPTER 3

Methodology

Design

A descriptive design was utilized for this study to examine patient's response to chemotherapy teaching. After receiving information on chemotherapy side effects and side effect management techniques, subjects were followed through one full cycle of their chemotherapy treatment. They were asked to complete a self-care behavior log to provide the researcher with information on what side effects they experienced, their perception of the intensity and distress of the side effect, and what self-care behaviors they performed to alleviate the side effect.

A descriptive design was chosen because it would be unethical to withhold chemotherapy teaching from the control group. It is the usual and customary practice to provide chemotherapy teaching in this research setting. The drugs that these cancer patients receive are very potent and have potential side effects which may endanger the life of the patient if the information is withheld.

Study site and Sample

This study was conducted in an office of three medical oncologists in a midwest resort community with a population of 70,000. Chemotherapy is administered by three chemotherapy certified registered nurses employed by the physicians. These nurses are also responsible for chemotherapy teaching.

All patients who met the following criteria were included: 1) 18 years or older, 2) read and write English, 3) mentally alert, 4) have a diagnosis of cancer, 5) receive a single agent or combination of chemotherapeutic agents for the first time 6) receive this chemotherapy in the physician's office, and 7) life expectancy of more than eight weeks.

The three registered nurses in the office identified potential subjects and determined their eligibility. Twenty subjects who met the criteria and agreed to participate were included in the study.

Protection of Human Rights

Approval to conduct this study was obtained from the Human Subject Review Committee at Grand Valley State University. The Oncologists also granted permission to utilize their patients in this study (Appendix C). Eligible subjects were approached by the office nurses to participate in the research. A consent form was signed after the study had been explained in detail (Appendix D). Each subject was also assured that involvement in the study would not cause

them any harm and that they were free to withdraw from the study at any time. Subject confidentiality was secured by assigning a code number to each name. The code numbers were used throughout the study.

Instruments

The instruments utilized in this study consisted of a demographic questionnaire and a Self-Care Behavior Log. The demographic questionnaire (Appendix E) elicited information on diagnosis, age, gender, marital status, educational level, occupation, living arrangements, identification of previous cancer treatment, and level of physical performance. The Karnofsky performance status scale identified the patient's performance on a scale of 100-10. A score of 100 indicated that the patient was able to carry on normal activity and work with no special care or assistance required and score of 10 indicated that the patient was unable to care for self and is moribund (Karnofsky, 1949). The Karnofsky performance scale was used to qualify subjects' functional ability at the time chemotherapy was initiated. Information obtained from the questionnaire, allowed the researcher to determine any relationships between the demographic variables of: age, sex, who they live with, educational level, occupation, and previous cancer treatment and functional ability.

The Self-Care Behavior Log (Appendix B) is a self-documentation tool which elicits the patients' reported side effects of chemotherapy and self care behaviors that

are performed in order to manage the side effects. This instrument was developed and implemented by Dodd (1982b, 1984a, 1984b, 1987, and 1988).

The tool was designed with two parts: a potential side effect self-care section and an experienced side effect self-care section. In the potential side effect section, a patient identifies the potential side effects they are susceptible to develop, actions that they may perform to prevent side effects of the chemotherapy drugs, and the name of the person who suggested the actions to prevent the side effects. In the experienced side effect self-care section, a patient records each side effect that is experienced after the chemotherapy treatment is given and indicates the date of the onset of the side effect. Patients also rate on a scale of 1 to 5, the intensity and distress of the side effect. A patient's perception of the effectiveness of the self-care behaviors are rated on another 5 point scale. The patient then identified the source (i.e self or nurse) of the suggestion of the side effect management. Only the experienced side effect section was utilized in this study because the researcher was interested in what side effect management behaviors the patients initiated after they experienced chemotherapy side effects.

Content validity of the Self-Care Behavior Log was established by two groups of oncologists and four clinical nurse specialists (Dodd, 1988). The reliability of the Self-Care Log was established by a test-retest method with a

control group. The overall management of side effect self-care behavior score at the pre and post intervention interview were significantly correlated, ($r=.88$, $p<.001$) in the control group patients (Dodd, 1988). Permission to use the tool was granted by the author (Appendix F).

Information teaching sheets on chemotherapy side effects and side effect management instructions were developed by Dodd (1987b). Permission to reproduce the teaching sheets for the study was granted by Appleton & Lange, Norwalk, Conn. (Appendix G). The teaching sheets were reviewed by the three office nurses and three physicians in the setting where the research was conducted. Revisions were made to correlate with the physicians' individual preferences of recommended side effect management techniques.

Procedure

The study was explained to eligible patients and consent to participate was obtained. Each subject received a 60 minute teaching session before their initial chemotherapy was started. During this session the researcher or office nurse asked the subject to complete the demographic questionnaire. Each subject was given a folder with written teaching sheets which included information on the recognition and management of side effects in relation to the specific agents used in their treatment. The teaching sheets served as a guide for the information that was presented by the nurses and investigator. A verbal

script of the information presented was also used to ensure continuity of instruction (Appendix H).

During this same session, the researcher or office nurse instructed the subject on how to complete the Self-Care Behavior Log. Detailed directions and an example of a completed log was given to each subject. To complete the log, subjects were required to record experienced side effects, indicate perception of intensity and distress of the side effect, and list self-care behaviors that were initiated to relieve the side effect. Each subject was instructed to complete the Self-Care Logs as the side effects occurred so that they would not have to rely on their memory.

The subjects were involved in one to two additional 30 minute sessions when they returned for their next chemotherapy treatment or blood work. These sessions included further explanation of the study and a review of the teaching information. The researcher and office nurses also reviewed the logs with the subjects at their next chemotherapy treatment to ensure that the log had been completed thoroughly.

The chemotherapy treatment cycle for these subjects ranged from three to six weeks depending on the treatment regimen. The teaching process was repeated with every patient but the frequency depended on when the subject was scheduled to return to the office. The length of time between each chemotherapy treatment varied from one week to

three weeks with the majority of patients returning within one week.

At the end of the first cycle, the Self-Care Logs were collected and any final entries were made in the Self-Care Log. Patients were assured that the office nurses were available to answer questions and to continue with chemotherapy teaching once the study was completed.

Chapter 4

Results

The types of data collected in this study were nominal and ordinal. Data were collected by the researcher and office nurses. After coding, descriptive statistics were used to analyze the data in this study. Quantitative data analysis of nominal and ordinal data was computed using percentages.

Characteristics of the Subjects

Nineteen of the twenty eligible subjects were included in this study. One subject was dropped from the study due to prolonged hospitalization resulting in inability to perform self-care behaviors. All of the nineteen subjects maintained the Self-Care Behavior Log through their first chemotherapy treatment.

The majority of the subjects in this study were married females who lived with their spouse and family. Educational preparation ranged from less than high school graduation to graduate school. (see Table 1.)

Table 1

Demographic Characteristics

N=19

Variable	Number	Percent
<u>Age</u>		
30-39	3	16
40-49	5	26
50-59	1	5
60-69	7	37
70-79	3	16
<u>Gender</u>		
Male	4	21
Female	15	79
<u>Marital Status</u>		
Married	16	84
Divorced/Separated	3	16
<u>Living Situation</u>		
Spouse/Family	17	89
Alone	2	11
<u>Highest Level of Education</u>		
Less than H.S. Grad.	4	21
High School Graduate	6	32
College	8	42
Graduate School	1	5

All of the subjects in this study were well enough to receive treatment as outpatients, therefore, their performance status was fairly high. Table 2 shows a breakdown of the subjects' performance status according to the Karnofsky's scale.

Table 2

Karnofsky Criteria Of Performance Status

Activity	Frequency	Percent
Able to carry on normal activity: no special care is needed		
100 Normal activity; no complaints, no evidence of disease	8	42
90 Able to carry on normal activity, minor signs or symptoms of disease	4	21
80 Normal activity with effort; some signs or symptoms of disease	4	21
Unable to work: able to live at home and able to care for most personal needs; a varying amount of assistance is needed		
70 Cares for self; unable to carry on normal activity or to do active work	2	11
60 Requires occasional assistance but is also to care for most of needs	1	5

The subjects received a variety of chemotherapy regimens for varying lengths of time from twenty-one to forty-two days. All of the subjects received these specific chemotherapy drugs for the first time. Thirty-six percent of the patients had received chemotherapy in the past (different drugs) and five percent of the patients had received radiotherapy.

Research Questions

1. What side effects were reported by persons receiving chemotherapy?

Since a variety of drugs were administered, the side effects profiles varied. Table 3 outlines the experienced side effects and the frequency in which they were experienced by the subjects. Nausea and diarrhea were reported most frequently. The side effects that the subjects experienced were immediate in nature and occurred within hours to days after treatment. Subjects did not report side effects of hematuria, leakage of chemotherapy at injection site, light sensitivity, or liver damage.

Table 3

Experienced Chemotherapy Side Effects

Side Effect	Frequency	Percent
Nausea and/or vomiting	16	84
Diarrhea	6	32
Hair loss	5	26
Mouth sores	5	26
Bleeding	2	11
Decreased appetite	2	11
Acne/skin rash	2	11
Anemia	1	5
Infection	1	5
Abdominal pain	1	5

Subjects had the opportunity to write down any other side effects or symptoms that they experienced during their treatment. These side effects and symptoms experienced by the subjects are identified in Table 4.

Table 4

Other Side Effects or Symptoms

Other Experienced Side Effects or Symptoms

Burning at incision site
Constipation
Discoloration of thumb nail
Dizzy, light headed
Dry mouth
Drowsiness
Fatigue/weakness
Hands sensitive to heat
Headache
Insomnia
Muscle and joint pain
Nervousness
Painful urination
Redness in arm and vein
skin rash, anal area
Sore, dry hands

2. How do patients rate the intensity of experienced side effects?

Subjects rated the intensity of the experienced side effect on a scale of 1 to 5 with 1 qualified as barely noticeable and five as most severe. The scale was regrouped into categories of low, medium, and high intensity at the time of data analysis. Subjects rated the intensity of the side effects that they were experiencing as low and medium more frequently than high intensity. The intensity ratings for the most frequently reported side effects are outlined in Table 5.

Table 5

Intensity Rating of Side Effect

Side Effect	Percent		
	Low 1-2	Medium 3	High 4-5
Nausea/vomiting	44	44	13
Diarrhea	67	34	0
Hair Loss	60	40	0
Mouth sores	80	0	20

3. How do patients rate the distress of the experienced side effects?

The subjects rated their perception of distress of the side effect on a similar scale from 1 to 5. A rating of one indicated that the subject perceived the side effect as a minor annoyance and a rating of five indicated that the side effect was extremely distressing. Again, the scale was regrouped into the categories of low, medium, and high distress at the time of data analysis. Subjects rated the distress of their experienced side effects as low in the majority of reported side effects. The distress ratings for the most frequent reported side effects are outlined in Table 6.

Table 6

Distress Rating of Side Effect

Side Effect	Percent		
	Low 1-2	Medium 3	High 4-5
Nausea/vomiting	56	31	13
Diarrhea	50	34	16
Hair loss	60	40	0
Mouth sores	80	0	20

4. What self-care behaviors (actions) did the patients initiate to alleviate or lessen the side effects of chemotherapy treatment?

The self-care behaviors that the patients performed for the most frequently experienced side effects are identified in Table 7. The actions were grouped into categories for easier interpretation. Other self-care behaviors that were reported for the less frequently reported side effects included: taking medications, diet alteration, increase fluid intake, increase rest, special skin care, and notifying the physician of symptoms.

Table 7

Self-Care Behaviors

Experienced Side Effect	Frequency	Percent
<u>Nausea and/or vomiting</u>		
Medication	63	68
Diet	20	22
Rest	6	7
Avoid eating	2	2
Exercise	1	1
<u>Diarrhea</u>		
Medication	9	60
Diet	3	20
Called Dr.	1	7
Did nothing	2	13
<u>Mouth Sores</u>		
Diet	8	57
Oral care	4	29
Medication	1	7
Did nothing	1	7
<u>Hair Loss</u>		
Wig	2	29
Scarf	1	14
Hair care	1	14
Did nothing	3	43

5. How do patients rate the effectiveness of each self-care behavior?

Subjects were asked to rate the effectiveness of the self-care behavior that they performed on a scale of one to five. A score of one indicated that the self-care behavior did not relieve the side effect and a score of five

indicated that the self-care action completely relieved the side effect. The scale was regrouped into categories of low, medium and high at the time of data analysis. Table 8 indicates how the subjects rated the self-care behaviors for the most frequently cited side effects. The self-care behaviors are listed in the order in which they were most often employed to deal with a particular side effect. Self-care behaviors which were identified less frequently as effective for nausea were exercising and avoiding eating; for diarrhea: calling the doctor; for mouth sores: taking medication; and for alopecia: wearing a scarf and hair care.

Table 8

Effectiveness of Self-Care Behavior

Side Effect	Percent Effective		
	Low 1-2	Medium 3	High 4-5
<u>Nausea/vomiting</u>			
Medication	9	26	65
Diet	36	23	41
Rest	29	14	57
<u>Diarrhea</u>			
Medication	27		73
Diet	25	25	50
<u>Mouth sores</u>			
Diet	50		50
Oral care	60	20	20
<u>Hair Loss</u>			
Wig	33		67

6. What was the most frequently identified source of information cited for the actions taken to manage the experienced side effects?

Patients were asked to identify where they obtained information on how to manage the side effects that they experienced. The most frequently cited source of information was the information sheets on side effect management that were provided by the investigator (33%). The subjects cited themselves (25%) as the second most frequent source of information and the doctor (17%) and

nurse (17%) less frequently. The subjects also obtained information from their spouse(3%), literature (2%) and home remedies (3%).

Overall, the subjects in this study reported experiencing an average of 2.33 side effects during their chemotherapy treatment and initiating an average of 5.64 self-care behaviors. Of all the self-care behaviors which were performed by the subjects, eighty-one percent were considered appropriate behaviors.

Chapter 5

Discussion/Implications/Conclusion

Discussion

The subjects in this study were provided with instruction on chemotherapy drugs, side effects and side effect management. Nursing research has documented that patients benefit from education about their disease and treatment. In addition, subjects benefitted from specific chemotherapy instruction. The results of this study are consistent with Dodd's (1988b) studies of subjects who received side effect management information.

The side effects most frequently reported in this study were nausea/vomiting, diarrhea, mouth sore, and hair loss. Other side effects that were reported less frequently were bleeding, decreased appetite, and acne/skin rash. Anemia, infection and abdominal pain were reported by one subject. None of the nineteen subjects reported experiencing hematuria (secondary to bladder toxicity), leakage of chemotherapy at injection site, light sensitivity, or liver damage.

There are several areas of interest to note from these results. First of all, nausea was the most frequently reported side effect while, decreased appetite was noted

less frequently. It seems logical that if patients experienced nausea that they would also have a decreased appetite. There are two possible explanations to account for these results. First of all, subjects reported taking medications as the most frequently initiated self-care behavior in response to nausea. Subjects may have experienced nausea, taken an anti-nausea medication and still have been able to eat. Thus, they may have not experienced a significant change in their appetite. The other explanation may be that subjects did not identify a decrease in appetite as a side effect of the treatment and related it to other factors such as the cancer itself. It is also interesting to note that although diarrhea was not severe (0 in high category), it was reported as extremely distressing (16% in high category).

Subjects rarely reported experiencing infection, anemia, and bleeding. These side effects usually occur as the result of bone marrow suppression caused by the chemotherapeutic agents. This often occurs months into the treatment course. Since the subjects in this study were only followed for one cycle, these side effects may not have developed until later in their treatment. Another interesting finding is that none of the subjects reported experiencing light sensitivity. This study was conducted during the months of October to April when there are fewer sunny days so the subjects were less likely to be exposed to sunlight.

Subjects also identified symptoms and side effects that may not be related to the chemotherapeutic agents. Some of these symptoms may be less common side effects or be related to medications the subjects were taking for treatment of an unrelated medical condition. Subjects were not asked to inform the researcher of other medical conditions or medications that they were taking.

The most frequently reported self-care measures in this study were taking medication, making diet selections, performing oral care, and wearing a wig. Dodd (1983, 1988b) did not report the actual self-care behaviors that her subjects initiated in so it is not possible to compare these findings.

The most frequently reported behavior in response to hair loss was "doing nothing". Eighty percent of the subjects who experienced hair loss rated the distress of the side effect as low. This may have occurred because they only experienced hair thinning which did not require the use of a wig. As their treatment progresses, they may lose enough hair to warrant the use of a wig.

The results of this study are congruent with the concepts of the Self-Care Deficit theory. A self-care deficit occurs as a result of a difference between self-care agency and the therapeutic self-care demand. The self-care agency is not able to meet the known therapeutic self-care demand. In this study, provision of information promoted the subjects' self-care agency by teaching them how to

manage their side effects that occurred as the result of their treatment. An increase in self-care agency resulted in a decreased therapeutic self-care demand.

Implications

The findings from this study have implications for nurses who provide teaching for patients who are receiving chemotherapy in inpatient and outpatient settings. Nurses in outpatient clinics/offices play a vital role in providing chemotherapy teaching. This teaching must include information on chemotherapy side effects and side effect management. The findings from this study indicate that in the initial phases of the treatment, patients need specific information on what side effects they are likely to experience first such as nausea/vomiting, diarrhea, mouth sores, and hair loss. The side effect management information needs to be directive and specific. Sixty-eight percent of the subjects in this study took medication as the number one self-care behavior. While it is the physician who prescribes the medication for the patient, it is the nurse's responsibility to ensure that the patient knows why and when he/she should take the medication.

These findings are also applicable to nurses who are responsible for chemotherapy teaching in the hospital. Even though patients generally do not perform as many self-care behaviors in the hospital, they are discharged in a relatively short period after receiving their chemotherapy. Patients continue to experience side effects at home and

need specific side effect management information in order to manage their care at home.

Caring for the cancer patient involves a multi-disciplinary approach including the physician, nurse, dietitian and pharmacist. Chemotherapy teaching should involve a collaborative approach using all of these disciplines to provide the most comprehensive care. Other disciplines need to know information about what patients are doing once they leave the treatment facility so that teaching can be tailored to meet the needs of the patients.

Nurse researchers need to continue to conduct studies to evaluate the effectiveness of chemotherapy teaching. There are very few research studies which evaluate the effectiveness of chemotherapy teaching which includes side effect management. Research needs to be conducted to evaluate chemotherapy teaching methods which focus on giving specific side effect management information for side effects that are experienced in the initial phases of the treatment so that patients are not so overwhelmed with information.

The direction of health care is to provide more services on an out patient basis. There is a great need for patients to know how to manage their care at home. Nurses need to know how effective their teaching is so they can modify their teaching programs to meet the individual needs of the patients.

Limitations

The limitations of this study are related to the small sample population, limited time for the study and the research tool. Although this research was conducted over a period of six months, only nineteen subjects met the criteria for inclusion in the study. This study was conducted during the months of October through April. Historically, the patient population is low during these months because much of the older population travels to southern portion of the United States. The small sample size limited the generalizability of the finding to the subjects included in this study.

Another limitation of this study is that the patients were not followed through their entire course of treatment which could last up to one year. Following the patients for a longer period of time could provide valuable information on how they managed side effects that usually occur later in treatment such as liver, bladder and heart damage. The researcher could also observe if subjects become more proficient at managing their care as they grew to understand what side effects they would probably experience. It is difficult to determine if some the side effects that the subjects experienced such, as nausea, were solely related to the chemotherapy drugs or were related to increased anxiety or related to receiving chemotherapy for the first time.

The complexity of the research tool was a limitation of this study. Subjects were required to make entries on many

elements which may have been overwhelming and confusing. Also, the terminology of the Self-Care Log was ambiguous. Subjects had difficulty conceptualizing the difference between the intensity and distress rating of the reported side effects.

The Self-Care Behavior log required subjects to make entries as they were experiencing side effects. This may have been difficult for subjects since they may have been feeling ill from their treatment. The completeness of the log depended on subjects' ability to express their perception of their side effects. Some patients were clearly able to identify what side effects they experienced and what actions they took but other subjects needed to be assisted with completing their log. Some subjects wrote detailed information and others wrote nothing. The subjects who wrote nothing were asked to remember what side effects they experienced at their next interview. The reasons for not making entries in their log were variable, including not feeling well enough to write. This may have resulted in a variance in the number of side effects reported due to prompting by the nurse or investigator.

The last limitation of this study was related to the inconsistent number of times the investigator or office nurse met with the subjects. The subjects who met more frequently may have been provided more teaching information. These subjects may have performed more self-care behaviors because they received more teaching.

Recommendations

In conducting a similar study, the investigator has several recommendations.

1. The original time frame of one treatment cycle was too short and should be increased to the full treatment course of treatment or at least six months.
2. Meet with every subject prior to the initial chemotherapy treatment and a minimum of every week there after until the investigation is completed.
3. Expand this study to other patient populations such as hospitalized patients and patients receiving radiation.
4. Measure the variable of coping for those subjects who received side effect management teaching versus those who did not receive side effect management teaching.
5. Develop a research design which focuses on sequencing teaching information on side effects that are experienced in the initial phase of treatment and add information as side effects are expected.
Compare this with the teaching method that was used in this study.
6. Omit the intensity rating in the Self-Care Behavior Log.
7. Side effect information sheets on fatigue/weakness should be added to the teaching program. This is universal side effect of chemotherapy and was only

identified by three subjects in this study. More subjects may have indicated that they experienced this side effect if it had been identified as an actual side effect of the treatment.

8. The side effect information on nausea and vomiting should be separated into individual categories. It would be helpful to know if the nausea is severe to the point of vomiting. If that is so, the seriousness of the side effect increases and the need for the patient to initiate self-care behaviors before their health is threatened.

Conclusion

This descriptive study focused on oncology patients who were receiving chemotherapy treatment in an physician's office. Using a Self-Care Behavior Log, subjects identified side effects they experienced, what self-care measures they performed and how they rated the effectiveness of the self-care action. The most frequently cited side effects were nausea/vomiting, diarrhea, mouth sores and hair loss. The most frequently identified self-care behaviors were taking medication, diet control, and wearing a wig. The subjects rated the effectiveness of these self-care behaviors between forty to twenty-five percent. The subjects reported that the information that was provided during the chemotherapy teaching sessions was the source they used the most to help them manage their side effects.

The findings from this study provided valuable information about patients' response to chemotherapy teaching. The results indicated that provision of side effect management information can increase the patients' ability to manage self-care thereby reducing the suffering endured from chemotherapy treatment. Oncology nurses need to continue to research and evaluate teaching methods which will enhance patient self-management and decrease side effects. Ultimately, oncology nurses can minimize chemotherapy side effects and promote a higher quality of life for cancer patients.

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APPENDIX A
CHEMOTHERAPY INSTRUCTIONS

Chemotherapy Instructions Guideline

Your chemotherapy instruction folder contains written information sheets on the chemotherapy drugs that you will receive and their possible side effects. It also contains written information sheets on how to manage the side effects which may occur as the result of your treatment.

Your folder also contains a Self-Care Behavior Log. You will be required to complete this log through one cycle of your treatment. Instructions on how to complete the log will also be in your folder. The research nurse or your chemotherapy nurse will give you instructions on how to fill in the log and will give you a written example of a completed log. Please follow the instructions and fill out the log as completely as possible.

Learning about your chemotherapy treatment and how to manage side effects is an on-going process that takes time but can be very rewarding. Please review the written information sheets frequently and feel free to ask any questions.

Chemotherapy Instructions

(Example Drug Information Sheet)

Paraplatin (Carboplatin)

<u>Possible Side Effects</u>	<u>Signs and Symptoms</u>
Nausea and vomiting	
Bleeding, low platelet count	Bruises, bleeding gums; nose bleeds; blood in your vomit may be bright red or coffee-ground-like; blood in stool may be red or black and tarry; blood in or sputum; flushed face.
Anemia, fewer red blood cells	More tired than usual; dizzy when you change positions; lightheadedness; pale membranes (lining) in your mouth and eyes; feel cold more often; insomnia; feel nervous. Mild chest pain or ache.
Infection, fewer white cells	Sore throat, cough, stuffy nose; burning when you urinate; shaking chills, diarrhea; burning (pain) when you have a bowel movement; pain, redness, swelling, or warmth of the skin; temperature greater than 100.5 F.; eye or ear drainage.
Kidney damage	pain in your flank area, blood in your urine, decreased urine out put.
Numbness tingling in hands and feet	clumsiness in hands and feet
Ringling in your ears	
Hearing loss	inability to hear normal tones

APPENDIX B
SELF-CARE BEHAVIOR LOG

Self-Care Behavior Log

Instruction

After you receive your chemotherapy you will be asked to identify any side effects that you experience. Take this log home and fill it out as completely as you can. Bring the log with you each time you come to the office.

Please list any side effects that you experience from your chemotherapy on your log. Circle the number that corresponds to the degree of severity and distress it is causing. Next, list any actions you took to alleviate (help or lessen) the side effect and circle how effective the actions were on the effectiveness scale. Finally, write in the names of the person, including yourself, who suggested the actions to alleviate the side effects.

Completing this log will take both time and effort, Please try to fill it out as thoroughly as you possible can. You will need to complete these logs through one cycle of your chemotherapy. The research nurse will review the log with you and provide a written example of a completed log.

SELF-CARE LOG

The Self-Care Log documents your experienced side effects from chemotherapy.

TO USE THE LOG, PLEASE DO THE FOLLOWING

- 1** Date and list each experienced side effect from your chemotherapy as it occurs.
 - Indicate how severe it is by circling the number that represents that feeling. "1" means it is barely noticeable; a "5" indicates it is very severe.
 - Indicate how distressing it is to you. "1", a minor annoyance; a "5", extremely distressing.
- 2** Describe any actions you took to prevent or relieve the side effect.
 - For each action you took, circle the number that represents how effective it was in relieving that side effect. "1", did not relieve it; a "5", completely relieved it.
- 3** List the source (person, including yourself, book, pamphlet, etc.) of suggestions for each action you took to prevent or relieve the side effect.

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code # _____

SIDE EFFECT

1 INTENSITY OF SIDE EFFECT						
BARELY NOTICABLE	1	2	3	4	5	MOST SEVERE

DISTRESS OF SIDE EFFECT						
MINOR ANNOYANCE	1	2	3	4	5	EXTREMELY DISTRESSING

2 DATE		ACTIONS TAKEN		NOT RELIEVED		COMPLETELY RELIEVED	
_____	_____	_____	_____	1	2	3	4 5
_____	_____	_____	_____	1	2	3	4 5
_____	_____	_____	_____	1	2	3	4 5
_____	_____	_____	_____	1	2	3	4 5

3 SOURCE FOR EACH ACTION TAKEN	
_____	_____
_____	_____
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_____	_____

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SIDE EFFECT

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1	INTENSITY OF SIDE EFFECT						
	BARELY NOTICABLE	1	2	3	4	5	MOST SEVERE
	DISTRESS OF SIDE EFFECT						
	MINOR ANNOYANCE	1	2	3	4	5	EXTREMELY DISTRESSING
2	ACTIONS TAKEN			NOT RELIEVED		COMPLETELY RELIEVED	
	1			1	2	3	4 5
	2			1	2	3	4 5
	3			1	2	3	4 5
	4			1	2	3	4 5
3	SOURCE FOR EACH ACTION TAKEN						
	1						
	2						
	3						
	4						

DATE _____

SIDE EFFECT

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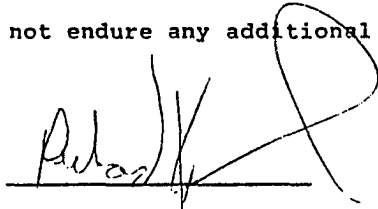
1	INTENSITY OF SIDE EFFECT						
	BARELY NOTICABLE	1	2	3	4	5	MOST SEVERE
	DISTRESS OF SIDE EFFECT						
	MINOR ANNOYANCE	1	2	3	4	5	EXTREMELY DISTRESSING
2	ACTIONS TAKEN			NOT RELIEVED		COMPLETELY RELIEVED	
	1			1	2	3	4 5
	2			1	2	3	4 5
	3			1	2	3	4 5
	4			1	2	3	4 5
3	SOURCE FOR EACH ACTION TAKEN						
	1						
	2						
	3						
	4						

APPENDIX C
RESEARCH SITE APPROVAL

Research Site Approval

Kelly Guswiler, R.N., B.S.N., Grand Valley State University Graduate Nursing Student, has my permission to conduct research with my patients in my office.

The purpose of this research is to investigate cancer patient's ability to initiate self-care behaviors following side effect management teaching. I understand that my patients will not endure any additional risks from this research.



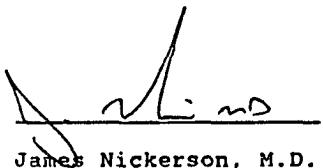
Richard Kosinski, M.D.

9/11/90

Date

1020 6th Street

Traverse City, MI. 49684



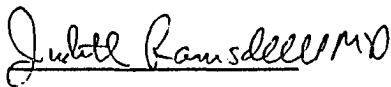
James Nickerson, M.D.

9/25/90

Date

1020 6th Street

Traverse City, MI. 49684



Judith Ramsdell, M.D.

9/11/90

Date

1020 6th Street

Traverse City, MI. 49684

APPENDIX D
SUBJECT CONSENT FORM

**Subject Consent Form
For
Participation in Clinical Investigation Project**

I understand that this study will examine what problems cancer patients experience following chemotherapy treatment and what things they do to help relieve them.

I also understand that:

1. participation in this study will involve three sessions. The first sessions will be conducted before your treatment begins and will include a questionnaire on personal background and chemotherapy teaching. This session will last one hour. The next two sessions will last 30 minutes and will be conducted at the second and third treatment visits. These sessions will continue with chemotherapy teaching and allow time for questions.
2. I will be required to complete a Self-Care Behavior Log throughout the duration of one cycle of chemotherapy treatment and I will bring the log to each of the interviews.
3. it is not anticipated that this study will lead to any physical or emotional risk to myself and I may benefit from learning more about my chemotherapy drugs, side effects, and side effect management techniques.
4. the information I provide will be kept strictly confidential and the data will be coded so that identification of individual participants will not be possible.
5. a summary of the results will be made available to me upon my request.

I acknowledge that:

"I have been given an opportunity to ask questions regarding this research study and that these questions have been answered to my satisfaction."

"In giving my consent, I understand that my participation in this study is voluntary and that I may withdraw at any time by notifying Kelly Guswiler or my chemotherapy nurse."

"The investigator, Kelly Guswiler, has my permission to review my office medical chart."

"I hereby authorize the investigator to release the information to the scientific literature. I understand that I will not be identified by name."

"I have been given Kelly Guswiler's phone number so that I can contact her at any time if I have questions."

"I acknowledge that I have read and understand the above information, and that I agree to participate in this study and complete the Self-Care Behavior Log."

Witness Signature

Participant Signature

Date

Date

APPENDIX E
QUESTIONNAIRE

Questionnaire

code#____

Please complete the questionnaire by answering the question, filling in the blank, or circling the correct response.

Age:____ Gender: a) female b) male

Marital Status: a) single b) married c) widowed
d) separated/divorced

With whom do you live with? a) alone b) spouse 4) family
d) friends

Educational Level: a) k-12 b) high school graduate
c) college

Occupation:_____

Cancer Diagnosis:_____

Any previous cancer treatment? a) yes b) no If yes, type____

Please check the number which best describes your activity level.

Karnofsky Criteria of Performance Status

Able to carry on normal activity: no special care is needed	___ 100	Normal; no complaints, no evidence of disease
	___ 90	Able to carry on normal activity, minor signs or symptoms of disease
	___ 80	Normal activity with effort; some signs of symptoms of disease
Unable to work: Able to live at home and cares for most personal needs; a varying amount of assistance is needed	___ 70	Care for self; unable to carry on normal activity or to do active work
	___ 60	Requires occasional assistance but is also to care for most of needs
	___ 50	Requires considerable and frequent medical care
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	___ 40	Disabled; requires special care and assistance
	___ 30	Severely disabled; hospitalization is indicated
	___ 20	Very sick; required hospitalization

APPENDIX F
PERMISSION FOR RESEARCH TOOL

School of Nursing
Department of Physiological
Nursing, N 611Y - Box 0610
San Francisco, CA 94143

University of California, San Francisco... A Health Sciences Campus



July 3, 1990


Kelly Guswiler
903 N. Marion Drive
Traverse City, Missouri 49684

Dear Ms. Guswiler,

I am writing on behalf of Dr. Marylin J. Dodd in response to your request for information regarding our Self-Care Behavior Log to measure self-care behaviors in cancer patients undergoing chemotherapy. You have Dr. Dodd's permission to utilize the Log in your research study.

Enclosed is the latest version of the Self-Care Behavior Log along with articles that may be of interest to you. If I can be of any further assistance, please do not hesitate to call me at (415) 476-5685. Dr. Dodd and I would be very interested in learning the results of your study.

Sincerely,


Suzanne L. Dibble, DNSc, RN
Assistant Adjunct Professor

Enclosures
SLD/fk

School of Nursing
Department of Physiological
Nursing, N 611Y - Box 0610
San Francisco, CA 94143-0610
FAX (415) 476-8800

UCSF
University of California, San Francisco...A Health Sciences Campus


May 13, 1991

Kelly Guswiler
Graduate Nursing Student
Grand Valley State University
Traverse City, MI 49684

Dear Ms. Guswiler:

I have received your request to include my Self-Care Behavior Log tool in your thesis manuscript and I am granting you permission. I understand that your thesis will be published with UMI Dissertation Services and will be registered with Masters Abstracts International.

Sincerely,


Marilyn J. Dodd, RN, PhD, FAAN
Professor and Interim Chairperson
Department of Physiological Nursing

MJD/jn

APPENDIX G
COPY RIGHT AUTHORIZATION

Appleton & Lange
25 Van Zant Street
East Norwalk, Conn. 06855

Dear Sirs:

I am requesting the permission to use sections of Managing Side Effects of Chemotherapy and Radiation Therapy: A Guide for Nurses and Patients (1987) by Marilyn J. Dodd.

I am a graduate nursing student at Grand Valley State University and writing my thesis. The title of my thesis is Cancer Patient's Ability to Initiate Self-Care Behaviors Following Side Effect Management Teaching. I plan to use Marilyn Dodd's Self-Care Behaviors Log as my tool and have received permission from Ms. Dodd. The sections of the book that I am interesting in using for my teaching intervention are included on pages 7,8,11,14,15,20, 21,31-36,40-41,44-45,47,48,50,51-54,57,58,61,62,70,71, and 76.

The information obtained from this book will only be used for academic purposes and will not be published.

Please send any correspondences to me at 903 N. Marion Dr.,
Traverse City, MI. 46684.

Thank you,

[REDACTED]
Kelly Gaswiler

PERMISSION GRANTED

*for thesis and
copy - please
return the
original.*

BY [REDACTED]

DATE

6/26/90

APPLETON & LANGE
FORMERLY
APPLETON-CENTURY-CROFTS

APPENDIX H
VERBAL SCRIPT

Verbal Script

My name is Kelly Guswiler or office nurse
_____. You are being asked to participate in this research study to help nurses examine what cancer patients experience following chemotherapy treatments and what things they can do to help relieve them.

Participation in this study will involve three teaching sessions. The first study will begin today and will last approximately one hour. During this session, I will review specific drugs that you will receive and possible side effects that you may experience. Next, I will review things that you can do to make yourself more comfortable or prevent serious complications once you have experienced a side effect. This is a lot of information to remember so I will give you a copy of every thing we talked about in your folder.

In your folder is a Self-Care Behavior Log (diary). This log will help me identify what actions you took once you experienced a drug side effect. Please fill out this log as completely as possible throughout your first cycle of chemotherapy. It is best to write down actions you performed once the side effects occurred. We will review an example log so you know how to complete one. Bring this log

Verbal Script (continued)

with you each time you come to receive a chemotherapy treatment. This log will not have your name on it and will only be identified by a code number.

The next two teaching session will occur at your next chemotherapy treatment. These session will last approximately 30 minutes. During these session(s), I will continue with the teaching. I will also go over your log with you.

There are no expected risks by your participation in this study. The teaching you receive is similar to what the other patients in this office receive.

Participation in this study is voluntary and you are free to withdraw at any time. Information obtained from this study will be kept strictly confidential.

If you have any questions at any time, please feel free to ask me or your office nurse. Our phone numbers are provided in your folder.