KNOWLEDGE OF HEALTH CARE TERMINOLOGY

IN PERSONS WITH CANCER

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KNOWLEDGE OF HEALTH CARE TERMINOLOGY IN PERSONS WITH CANCER

An Abstract of a Thesis by
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The problem. The purpose of this study was to assess the knowledge of health care terminology in persons with a diagnosis of cancer.

Procedure. The Informational Questionnaire and Health Care Terminology Questionnaire were mailed to a sample of 2,684 persons with cancer. The sample was selected from the cancer registry of a midwestern hospital. The Informational Questionnaire consisted of questions about sex, marital status, educational level, ethnic origin, number of hospitalizations, health care professionals in the family, perceived knowledge level, length of cancer diagnosis, age and size of the community. The Health Care Terminology Questionnaire was a 50-question multiple choice test measuring knowledge of health care terminology.

Findings. There were significant differences in the knowledge of health care terminology when the sample was categorized by sex, educational level, the presence of health care professionals in the immediate family, perceived knowledge level, size of the community, age, marital status and ethnic origin ($p < .05$). There were no significant differences in the knowledge of health care terminology when the sample was categorized by length of cancer diagnosis and number of hospitalizations.

Conclusions. The knowledge persons with cancer had of health care terminology varied depending on demographic variables. In assessing learning needs of persons with cancer, knowledge of health care terminology and variables which might influence such knowledge are vital for a thorough assessment.

Recommendations. Recommendations for further research include the following: develop and test a new tool with more technical health care terminology; assess clients' knowledge of more technical health care terminology; and assess the knowledge of health care terminology in other client populations.
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CHAPTER 1
DIMENSIONS OF THE PROBLEM

With the advent of Diagnostic Related Groups (DRG’s), prospective payment, and sick patients leaving the hospital earlier, patient education has had an increasingly important role in patients' self-care after leaving the health care arena. In addition, other factors such as the rising cost of health care, the current emphasis on health and wellness and the increased sophistication of the health care consumer has affected the patients' self-care. Hochbaum (1980) suggested that one reason for the increased attention to patient education is that the treatment of today's foremost diseases are vastly more complex and technologically sophisticated than the treatments in earlier days, and they require far more active participation on the part of the patient. With the importance of patient centered education, the understanding of basic health care terminology used by health professionals is important if the education process is to continue with learning and behavior change as the goals.

There have been studies describing the knowledge of health care terminology in a variety of types of patients and settings (Bourhis, Roth, & McQueen, 1989; Byrne & Edeani, 1984; Gibbs, Gibbs, & Henrich, 1987; Samora, Saunders, & Larson, 1961; Smeltzer, 1980; Spiro & Heidrich, 1983). These studies determined that there was some misunderstanding of
health care terminology by clients.

Purpose

The purpose of this study was to investigate the actual knowledge of health care terminology in persons with cancer. Perceived knowledge level of health care terminology, educational level, marital status, length of time of cancer diagnosis, number of hospitalizations, presence of health care professionals in the family, age, ethnic origin, sex and size of the community were the variables which were considered in analyzing data. This study was a partial replication of a study done by Byrne and Edeani (1984).

Definition of Terms

The following definitions of terms were used in this study:

(a) Health care terminology: The health care terminology consisted of words frequently used by health care professionals in conversations with patients or in written health care literature pertaining to an individual's health or disease state. These were analyzed in terms of perceived knowledge level and actual knowledge.

(b) Perceived knowledge level: The subjects indicated the knowledge level they believed they possessed about the health care terminology used by health professionals according to
three levels: very knowledgeable, fairly knowledgeable and not knowledgeable.

(c) Actual knowledge: The Health Care Terminology Questionnaire measured the actual knowledge of definitions of health care terms in the subjects.

(d) Persons with cancer: These persons are registered with Oncology Data Services at a 710 bed private midwestern medical center based in a community with 250,000 people. All individuals who are diagnosed with cancer by their physicians or receive cancer treatment at this center are registered with Oncology Data Services. Once the diagnosis of cancer is made, the person remains with the registry whether or not the cancer is in remission until death. Those persons listed with the registry are not all considered terminally ill. Oncology Data Services uses most of the data to indicate survival rates for various types of cancer. Oncology Data Services has four methods to ensure each individual with a diagnosis of cancer is included in the registry: malignant pathology reports, radiation therapy registration reports, medical records index, and year end pathology reports.

Hypotheses

Ten hypotheses were tested.

1. There will be a significant difference in actual knowledge of health care terminology when the subjects are
categorized by perceived knowledge level of health care terminology.

Rationale: Byrne and Edeani (1984) found perceived knowledge level of health care terminology to be significantly related to actual knowledge of health care terminology in hospitalized patients with a variety of diagnoses. Because persons with cancer have been hospitalized at least once to receive a cancer diagnosis they may perceive they have a higher knowledge level.

2. There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by educational level.

Rationale: One would expect those subjects who attended school longer would score higher on a test of health care terminology. Byrne and Edeani (1984) found educational level to be significantly related to actual knowledge of health care terminology in hospitalized patients with a variety of diagnoses. This was also a finding of Gibbs, et al. (1987), Samora, et al. (1961), Shaughnessy (1988), Smeltzer (1980) and Spiro and Heidrich (1983). Although the findings have been consistent, the variable of educational level needs to be readdressed due to the increased focus on health in this country.
3. There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by marital status.

   Rationale: It is proposed that subjects who share a household with another person may share more information related to health.

4. There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by length of cancer diagnosis.

   Rationale: One would expect those subjects who have been aware of their diagnosis for a longer period of time to score higher on a test of health care terminology because of more frequent contacts with health care personnel.

5. There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by number of hospitalizations.

   Rationale: Those subjects with more hospitalizations may have more opportunities to ask questions about health care terminology due to their increased exposure and increased familiarity with the health care system.

6. There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by the presence or absence of health care professionals in the subject's immediate family.
Rationale: Those subjects with health care professionals in their immediate family have increased exposure to health care terminology and more opportunities to ask questions than those without health care professionals in their immediate family. Spiro and Heidrich (1983) found those subjects with medical training had higher scores on a test of seven health care terms.

7. There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by age.

Rationale: Byrne and Edeani (1984), Shaughnessy (1988), Smeltzer (1980) found age to be significantly related to actual knowledge of health care terminology. Shaughnessy found increasing age to be associated with a decline in the number of correct answers on a test of health care terminology.

8. There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by ethnic origin.

Rationale: Samora, et al. (1961), Smeltzer (1980) and Shaughnessy (1988) found differences among ethnic origins in the amount of understanding of health care terminology. In the past decade, there has been an increase in ethnic diversification in the State of Iowa.
9. There will be no difference in actual knowledge of health care terminology when the subjects are categorized by sex.

Rationale: While Byrne and Edeani (1984) found no difference between sex and actual knowledge levels of health care terminology, Shaughnessy (1988) found that women performed significantly better than men. This researcher proposes that there is not a difference related to sex because men and women are basically equal in knowledge.

10. There will be no difference in actual knowledge of health care terminology when the subjects are categorized by the size of the community in which they live.

Rationale: The size of a community may not relate actual knowledge since some smaller as well as larger communities have adequate health care facilities.

Theoretical Basis of the Study

Orem's Self-Care Deficit Model of nursing provided the theoretical basis for this study. Orem (1991) defined self-care as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 117). Self-care activities are becoming more important because the current health care system
requires individuals to be more responsible for their own health. Orem (1991) pointed out that a patient requires knowledge in order to provide self-care. "Providers of self-care require two kinds of knowledge: empirical knowledge of events and of internal and external conditions and antecedent knowledge that aids them in making observations, attaching meaning to their observations, and correlating the meaning of events and conditions with possible courses of action" (p. 164). It is logical that nurses need to determine whether patients understand the health care terms used in their care. Orem's Self-Care Deficit Model of nursing will be discussed further in Chapter 2.

Significance to Nursing

Patient and health education has been mandated by the American Nurses' Association's (ANA) Model Nurse Practice Act (1976), the Oncology Nursing Society (1989), the Joint Commission on Hospital Accreditation Organization (1987) and the American College of Surgeons Commission on Cancer (1986). Assessment of a patient's knowledge of health care terminology offers a starting point for individualizing patient education. "Assessing patients probably is the most important activity nurses can undertake in an effort to provide instruction in an efficient and effective manner" (Ruzicki, 1989, p. 630).
Knowledge of health care terminology is important for all patients, but it is particularly important for persons with cancer due to the nature of their treatments and extended contact with the health care system. For nurses working with persons with cancer, assessment of the understanding of general health care terminology which patients' possess is important. If the terminology is misunderstood, it is possible that the more specific cancer terminology used in cancer patient education also will be misunderstood. Nurses must continually strive to improve nursing interventions to help persons with cancer and their families.

Gibbs, et al. (1987) stated "With daily changes in diagnostic and therapeutic technology, and with an increasing expectation that patients take some responsibility for their own health care, the question of patient understanding of commonly used medical vocabulary should be readdressed periodically and in different patient populations" (p. 176). This study is responsive to the recommendations of Gibbs, et al. by readdressing the understanding of health care terminology in a specific population. Former studies have not had as a sample only persons with cancer. Since cancer is the second highest cause of death in the United States, it is particularly timely to investigate knowledge of health care terminology in this group.
CHAPTER 2

REVIEW OF THE LITERATURE

The purpose of this study was to investigate the actual knowledge of health care terminology in persons with cancer. Perceived knowledge level of health care terminology, educational level, marital status, length of time of cancer diagnosis, number of hospitalizations, presence of health care professionals in the family, age, ethnic origin, sex and size of the community were variables which were considered in analyzing data. In this chapter, literature related to Orem's Self-Care Deficit Model, studies testing knowledge of health care terminology and the incidence of cancer are reviewed. The review concludes with a summary of the literature.

Orem's Self-Care Deficit Model

Orem (1991) described three theories which constitute a general theory of nursing or the Self-Care Deficit Model of nursing. These three theories are a theory of self-care, a theory of self-care deficit and a theory of nursing system. Orem described the Self-Care Deficit Model of nursing as a synthesis of the theoretical concepts self-care (and dependent care), self-care agency (and dependent-care agency), therapeutic self-care demand, self-care deficit, and nursing agency. The self-care agency and therapeutic self-
care demand are patient variables while nursing agency is a nurse variable. The two patient variables are related. Self-care agency is the individual's capabilities and actions for self-care and therapeutic self-care demand is the demand an individual faces for the capabilities and actions to meet needs. Nursing agency can be related to both patient variables when the incapacity and actions are limited because of health state or health care needs of the care recipient. Orem (1991) described self-care from a nursing point of view. "Human beings are viewed as needing continuous self-maintenance and self-regulation through a type of action named self-care" (p. 73). Orem described this regulation in the form of three types of requisites: requisites required by all individuals regardless of age; requisites related to human developmental processes; and health-deviation requisites which arise from or are associated with persons' health states and associated health care. The health-deviation self-care requisite has particular significance to this study. Orem stated "If persons with health deviations are to become competent in managing a system of health-deviation self-care, they must also be able to apply relevant medical knowledge to their own care" (p. 99).

Orem (1991) also explained that there are limitations of knowledge. These limitations include new experiences which are not understood, new requirements for self-care, new
self-care requisites within a prescribed regimen of health care and the lack of knowledge to meet these requisites. These limitations contribute to self-care deficits.

When a self-care deficit is identified, nursing intervention is necessary. The nursing intervention which applies to this study of knowledge of health care terminology best is the supportive-educative system of nursing. The supportive-educative system "is for situations where the patient is able to perform or can and should learn to perform required measures of externally or internally oriented self-care but cannot do so without assistance" (Orem, 1991, p. 291). The patient's requirements for help are decision making, behavior control and acquiring knowledge and skills. These variations can apply to situations involving patients and common health care terminology, but the action taken depends upon the patient's assessed knowledge level.

Knowledge of Health Care Terminology

It is widely accepted that in order to communicate effectively, terminology used must be understood by both parties. Suggestions have been made regarding the importance of using simplified health care terminology when communicating with patients (Apse & Stetler, 1985; Bourhis, Roth & McQueen, 1989; Breeze, 1987; Byrne & Edeani, 1984; Cosper, 1977; Gibbs, Gibbs & Henrich, 1987; Holden, 1985;
Miller, 1985; Samora, Saunders & Larson, 1961; Shaughnessy, 1988; Smeltzer, 1980; Spiro & Heidrich, 1983). Several studies have investigated actual understanding of health care terminology.

This section of the literature review begins with a review of the study by Byrne and Edeani (1984) which was partially replicated. Byrne and Edeani studied the perception of knowledge of health care terminology compared with the actual knowledge of health care terminology. The authors proposed three hypotheses: (1) There is a significant difference between staff perception of patient's knowledge of medical terminology and the patient's actual knowledge of medical terminology; (2) Age, sex, education, perceived knowledge, length of illness and number of times hospitalized are each significantly related to a patient's level of knowledge of medical terms; and (3) There has been a significant increase in patients' knowledge of medical terms between 1961 and 1980.

The sample consisted of 125 patients who were admitted to the medical unit and outpatient clinic of a general hospital. Byrne and Edeani (1894) wanted to sample from a more general population than had been done previously. The patients were diagnosed as having one of the following diseases: cardiovascular disease, hypertension, diabetes, cancer or other unclassified medical conditions. The
patients were interviewed within their first three hospital days using the 50 question multiple choice tool regarding common medical terminology.

The results demonstrated that no respondent answered all 50 questions correctly, and no question was correctly answered by all 125 respondents. The range of scores was 4 to 48 with a mean of 36 and standard deviation of nine.

The first hypothesis demonstrated there was a significant ($t = 17.5, p < .01$) difference between staff perception of patients' knowledge of medical terminology and the patients' actual knowledge. The staff expected a patient to understand all the terminology.

In the second hypothesis only age, educational level, and perceived level of knowledge were significantly correlated with actual knowledge. The level of knowledge decreased with age, particularly in the older-age categories ($r = -.2253, p < .05$). The highest scores were found in persons in the 31-70 age bracket, the lowest scores in the 71+ bracket, and the under 30 age bracket also demonstrated less knowledge than the mid-age bracket. As educational level increased, the scores increased ($r = .5782, p < .001$). When comparing perceived level of knowledge with actual knowledge, the respondents were asked to rate themselves in terms of their knowledge of medical vocabulary. Twenty-four percent of the respondents felt very knowledgeable; 66\%
fairly knowledgeable, and 10% not knowledgeable. The perceived knowledge levels were significantly correlated with the actual knowledge levels ($r = .2174, p < .05$). Byrne and Edeani (1894) summarized this finding by indicating that if patients felt they were knowledgeable about a subject, the patient educator could use this as an assessment tool for patient education. They cautioned that level of knowledge is not determined by self-evaluation only, and other assessments must be conducted.

To test the third hypothesis, ten words from this study were compared with the same ten words studied by Samora, et al. (1961) 19 years before. There was an overall improvement in patient awareness of health care terminology. For the term "abdomen" there was a significant decrease: two terms, "symptom" and "constipation," showed no significant increase, while the remainder of the ten terms showed a significant increase. Byrne and Edeani (1894) believed that medical terminology usage had improved but that the lack of understanding by patients continued to be a problem that needed to be addressed. They related the poor understanding of medical terms to changes in the medical system. The authors offered recommendations that called for orientation programs for staff to warn of the problems of using medical terminology. To help the patients, these authors recommended orientation programs and a reference of commonly used
terminology for patients (Byrne & Edeani, 1984).

One of the earliest studies of health care terminology was conducted by Samora, et al. (1961). The subjects consisted of 125 patients of White, Hispanic American, and African American backgrounds from a public hospital. A random sample of 50 words was chosen from a larger list that contained words submitted by physicians, interns, and senior medical students. Before the final 50 words were picked, a group of non-health professionals and nurses reviewed the terms and those that had not achieved 100% reproducibility were eliminated from the list. Each patient was then interviewed with a tool that used each word in context in a sentence and scored as having no understanding, vague, ambiguous, or wrong understanding, or reasonably clear and complete understanding.

The results demonstrated a significant relationship between educational level and the responses indicating understanding. Those with more formal education performed better, but the researchers did not expect the relatively low scores in the reasonably clear and complete understanding category from those patients with 10 to 11 years of formal education.

The results also demonstrated a significant relationship between ethnic group and understanding of medical terms. The performance of Whites and African
Americans were similar but Hispanic Americans gave fewer results in the reasonably clear and complete understanding category and more in the no understanding category. A possible reason for this was the language barrier. No differences in knowledge level were found when the sample was categorized by age and sex. Overall, the authors found performance to be poor enough to suggest that a good deal of what is said in a hospital and clinic to patients of average or even better educational background may not be clearly understood (Samora, et al., 1961).

Smeltzer (1980) also studied health care terminology but unlike Samora, et al. studied the recognition and understanding of common as well as medical hypertension terminology. The subjects consisted of 30 male patients with hypertension who were selected during their visits to a renal ambulatory clinic. There were 19 White and 11 African American persons in the sample. The selected terminology consisted of ten health care terms and five common terms from a patient education booklet. The patients were asked the definitions of the words (not in context) in an interview and the answer was recorded as a correct definition, incorrect definition or no answer. The patients also were asked to note if they recognized the term as one that had been used by a doctor or nurse.

The results indicated that race, educational level and
age were statistically significant indicators in the understanding of medical terminology, but that duration of diagnosed illness, severity of the disease, and whether the patient was hospitalized in the last year were not significant indicators. The African American patients defined medical terms correctly at a mean rate of 30.9%, while the White patients defined a mean of 54.7% correctly. Those patients who had less than an eighth grade education defined medical words correctly at a mean rate of 11.7% compared to the mean of 43.5% by those with an eighth to twelfth grade education and a mean of 81.4% by those with more than a twelfth grade education.

Hypertensive patients between the ages of 50 and 59 years understood an average of 74% of the medical terms. A positive correlation between the number of common words understood and the number of medical words understood by the hypertensive patient was reported. Results indicated that hypertensive patients have recognized or heard words used in relationship to their disease but did not know what the words meant (Smeltzer, 1980). Smeltzer suggested each patient should be assessed before teaching is conducted and simple terminology should be used when communicating with patients about their disease.

Spiro & Heidrich (1983), like Smeltzer, studied the knowledge of health care terminology using the same variables
of age and educational level. They studied eight terms rather than fifteen terms and the relationship between medical background and knowledge of health care terminology. Their sample consisted of 166 patients at a family practice clinic. The patients indicated their age, educational training, sex, and medical background. The list of eight terms was identified from previous patient interviews. These were words used often in clinical settings without further explanation. The patients were given a questionnaire that asked them to identify which words they had heard within the health care setting and to identify as true or false three to four statements regarding each term. The eight terms were hypertension, virus, strep throat, herpes, hematocrit, tumor, Pap smear, and uterus. The results were tabulated as a percentage of maximum number of correct responses for each item.

The results showed no difference in scores for male and female subjects on any of the items. Subjects with medical training had higher scores than those who lacked such training on all eight items, with statistical significance reached for three items (virus, herpes, and Pap smear). Significant differences among the four age groups were demonstrated only for strep throat and herpes. The patients with higher educational training had significantly higher scores for every term. Overall, the authors indicated the
findings demonstrated substantial misconceptions of a broad range of common terms by a broad range of adult patients and that patients' understandings can be quite different even among those expected to be more knowledgeable (Spiro & Heidrich, 1983).

Gibbs, et al. (1987) correlated knowledge of health care terminology with the variables of age, sex and educational level as did Spiro and Heidrich. The source of information about health care terms and how this source affected subjects' understanding of terms were also studied. The data were collected from 50 patients randomly chosen from men and women over the age of 17 from a clinic setting. Only patients born in the United States who spoke English as their native language were included in the study. The data were obtained through interviews during which the patient was asked to verbally define each of the 15 medical terms. The answers were placed in three categories: a workable understanding of the word; incorrect or vague definition; and no knowledge. Of the responses, 63% were correct, 26% vague or wrong and 11% were categorized as no knowledge.

The sources of information given were physician visit, reading, television, associates and friends or none. Those who said reading was their main source of information scored significantly higher than other groups (p < .05). The data demonstrated that readers had significantly more education
than other groups and education itself correlated with higher scores. The study pointed out that visits to physicians and written information did not assure adequate patient education.

Overall, the results reported a relatively poor patient comprehension of medical vocabulary. The variables of age, sex, and race did not significantly correlate with the comprehension of medical vocabulary. Level of education was found to correlate positively with vocabulary test performance. Gibbs, et al. (1987) concluded that misunderstanding of medical vocabulary could interfere with all aspects of health care.

Shaughnessy (1988) also studied the understanding of health care terminology when the population was categorized by the variables of age, race, sex and educational level. Shaughnessy interviewed 145 patients to determine their knowledge of 14 frequently used pharmacy terms and to identify demographic factors associated with differences in levels of knowledge. The patient's word definitions were graded as correct, vague or ambiguous, incorrect or unknown. Subjects correctly identified only 53% of the terms.

Unlike Gibbs, et al. (1987), Shaughnessy (1988) found age, sex, and race to be significantly correlated to knowledge of pharmacy terms. White subjects had significantly more correct answers than African American
subjects ($p = .0001$). Women performed significantly better than men ($p = .0290$). Subjects with less than a high school education on an average defined only 5 of 14 terms correctly while those with at least 12 years of education correctly answered an average of 8.41 terms ($p = .0001$). The investigator reported that a decline in the number of correct scores was associated with increasing age. In general the difference was significant only between the youngest and oldest age groups ($p = .0149$).

Unlike prior studies, Bourhis, et al. (1989) studied the use of medical language (ML) and everyday language (EL) among patients, doctors, and nurses. There were no specific health care terms studied. This study discussed broadly the communication problems encountered among doctors, nurses, and patients when medical language is used. The sample was composed of 40 physicians, 40 patients, and 40 nursing students who were told they were completing a survey on doctor/nurse/patient communication in the hospital setting. The three groups were recruited on a voluntary basis. The patients had to have been hospitalized for a period of at least two days within the last two years to participate in the study.

The written questionnaire provided definitions of medical language and everyday language and consisted of four sections. The first section was a self-report of the
percentage of medical language (ML) and everyday language (EL) the respondent employed with patients, nurses, and doctors in the hospital setting. In the second section, respondents estimated the amount of ML and EL employed by other members of their own group and nurses and doctors when communicating with patients, nurses, and doctors. The third section sought evaluative ratings (on a seven point scale) of the appropriateness of ML/EL use among patients, nurses and doctors in the hospital setting. The final section dealt with background information on respondents and their attitudes concerning different communications issues in the hospital setting.

The results indicated there were significant differences in the degree of ML spoken and comprehended by health professionals and patients, with medical professionals equally at home with EL and ML and patients reporting less fluency ($F(2, 117) = 93.60, p < .001$) and comprehension ($F(2, 117) = 103.04, p < .001$) with ML than with EL. There was an overall significant difference in amount of ML spoken by health professionals and patients with ML spoken more often by health professionals than by patients ($F(2, 118) = 20.30, p < .001$).

The amount of ML used depended on to whom the respondent was speaking: more ML was used when speaking with health professionals than with patients. There were
significant differences between estimations of ML provided by nurses, patients and doctors when the estimations were of doctors' ML/EL usage ($F(2, 101) = 7.68, p = .001$). Neither nurses or patients perceived doctors as switching to EL with patients as much as doctors asserted they did, and the nurses and patients suggested the doctors used more ML with patients than the doctors said they did.

The three groups agreed that communication courses for health professionals were quite valuable, while courses for patients might be somewhat valuable. The authors stated that an important finding in this survey supported the notion of the nurse as a "communication broker" (p. 344) who converged linguistically to both the EL of the patient and the ML of the doctor. The nurses' self reports and the perceptions respondents had of the nurses ML/EL use reflected the nurses' role as a "communication broker" between doctors and patients in the hospital setting. Also, the three groups of respondents believed the use of ML had frequently led to communication difficulties between health professionals and patients while the use of EL only rarely led to such problems (Bourhis, et al., 1989).

Several authors (Mathews, Thornton & McLean, 1988; Morra, 1988; Schwalb & Crosson, 1988) have discussed the importance of clear medical terminology in the written form, such as the pamphlets and booklets that have been written
covering various health problems. Mathews, et al. hypothesized that the reading-grade level of written patient education material would exceed the reading-level ability of the average American. When the effect of vocabulary training was accounted for, there would be a significant reduction in the reading-grade level of the patient education material.

Thirty patient education pamphlets dealing with respiratory diseases were chosen. Ten pamphlets were chosen at random for the study. The SMOG index was used to determine readability. The SMOG index score indicated a reading-grade level of written patient education materials higher than the reading-level ability of the average American. The second hypothesis was supported after showing a significant reduction ($p < .05$) in the level of reading difficulty after identification of words with meanings that should be taught to the reader as an introduction to the patient education material. The authors said that a limitation of their study was that the SMOG index can only predict a level of reading difficulty based on an analysis of sentence and word length, and cannot take into account the within-individual variables that affect the reader and the actual content of the materials.

Incidence of Cancer

According to Cortan, Kumar and Robbins (1989), the word
cancer is synonymous with the term malignant neoplasm. A neoplasm is an abnormal growth of tissue which serves no purpose and can damage the host. The neoplastic tissue competes with normal cells and tissues for energy supplies and nutrition. A neoplasm may be benign or malignant. A benign neoplasm is an abnormal growth of tissue that is relatively harmless and does not spread to and infiltrate other tissues. A malignant neoplasm can spread or metastasize to other tissues far removed from the site of origin. Carcinoma in situ is a neoplasm that remains confined to the site of origin but can be invasive if not removed.

Cancer is the second highest cause of death in the United States (American Cancer Society, 1991). According to 1991 estimates by the American Cancer Society, the most frequently occurring cancers in men will be cancers of the prostate (22%), lung (19%) and colon and rectum (14%). Prostate cancer in 1991 will cause 12% of cancer deaths, lung cancer will cause 34% of cancer deaths and colon and rectum will account for 11% of all cancer deaths in men. In women the most frequent cancers are breast (32%), colon and rectum (14%) and lung (11%). In 1991, lung cancer will account for 21% of cancer deaths in women with breast being second with 18% and colon and rectum causing 13% of cancer deaths. These statistics exclude non-melanoma skin cancer. In Iowa there
will be an estimated 13,100 new cancer cases in 1991 with 6,200 estimated deaths.

An estimated 555,000 females and 545,000 males will develop cancer in 1991. It is also estimated that 272,000 males and 242,000 females will die of cancer in 1991.

Summary

The findings of studies regarding knowledge of health care terminology were inconsistent. Byrne & Edeani (1984), Smeltzer (1980), and Shaughnessy (1988) reported age to be significantly related to the knowledge of health care terminology while Samora, et al. (1961), Spiro & Heidrich (1983), and Gibbs, et al. (1987) found age to be nonsignificant.

When race was correlated with the knowledge of health care terminology, Samora, et al. (1961), Smeltzer (1980) and Shaughnessy (1988) reported significant findings while Gibbs, et al. (1987) did not. Shaughnessy (1988) was the only researcher to find sex to significantly correlate with knowledge of health care terminology.

Byrne & Edeani (1984) and Smeltzer (1980) found the variables of length of illness and number of hospitalizations not to be related to the knowledge of health care terminology. Spiro & Heidrich (1983) were the only researchers who considered the variable of health care
background of the subject and reported significant findings among subjects with a health care background and knowledge of health care terminology. Gibbs, et al. (1987) were the only researchers to consider the source of information as a variable for understanding health care terminology. Those who listed reading as the source of information scored significantly higher on knowledge of health care terminology. Byrne & Edeani (1984) found a significant correlation between perceived knowledge of health care terminology and actual knowledge of health care terminology.

None of the studies considered the variables of marital status, size of the community in which the person lived or health care professionals in the family in relation to knowledge of health care terminology. Studies which correlated educational level with knowledge of health care terminology reported significant findings (Byrne & Edeani, 1984; Gibbs, et al., 1987; Samora, et. al, 1961; Shaughnessy, 1988; Smeltzer, 1980; and Spiro & Heidrich, 1983).

The most recent study concerning the actual understanding of health care terminology was conducted by Shaughnessy (1988), measuring the understanding of health care terminology in clients using the services of a pharmacy. This researcher was unable to locate studies conducted by nurses regarding health care terminology since the study of Byrne and Edeani (1984). Since there is a void in the
literature related to the knowledge of health care terminology in persons with cancer, this research study is appropriate.
CHAPTER 3
METHODOLOGY

The purpose of this study was to investigate the actual knowledge of health care terminology in persons with cancer. Perceived knowledge level of health care terminology, educational level, marital status, length of time of cancer diagnosis, number of hospitalizations, the presence of health care professionals in the family, age, ethnic origin, sex and size of the community were variables which were considered in analyzing data. In this chapter the research design, instruments, sample, rights of human subjects and data collection procedures are described.

Design of the Study

This was a descriptive study. Polit and Hungler (1987) defined descriptive research as "research studies that have as their main objective the accurate portrayal of the characteristics of persons, situations, or groups and the frequency with which certain phenomena occur" (p. 142). The descriptive approach was appropriate because this study surveyed the knowledge persons had of health care terminology.

This study partially replicated the investigation of Byrne and Edieani (1984). Differences were the population
studied, statistical analysis and a slight modification of the questionnaire. Polit and Hungler suggested that replication is extremely useful and that much greater confidence can be placed in the findings of a study if it can be demonstrated that the results can be replicated.

Instruments

Two data gathering instruments were used, the Informational Questionnaire and the Health Care Terminology Questionnaire. Each is described.

The Informational Questionnaire (Appendix A) is a modification of the questionnaire used by Byrne and Edeani (1984). Current terminology replaced some outdated terms (e.g. Anglo and Negro). The data requested were sex, marital status, educational level, ethnic origin, number of hospitalizations for cancer, the presence of health care professionals in the subject's family, age, length of cancer diagnosis, and the size of the subject's community. In addition, each subject was asked to rank self as to the level of knowledge of health care terminology possessed, i.e., very knowledgeable, fairly knowledgeable and not knowledgeable.

The Health Care Terminology Questionnaire (Appendix B) was a modification of the tool used by Byrne and Edeani (1984). The revisions made in the tool were editorial in nature. Inconsistencies between the stem and response in the
multiple choice questions were corrected. Stereotypically sexist terms were eliminated. The content of each question was retained. One term, autopsy, was excluded due to the sensitivity of the question in persons with cancer. This term was substituted with metastasis, a term frequently used by health care professionals in caring for persons with cancer. Permission was obtained from Jean Byrne to use the tool (Appendix C).

Byrne and Edeani (1984) developed the tool using specific processes. A list of common health care terms was compiled from interviews with patients, health care staff, and various health information booklets in use in the hospital. A list of 125 terms was then submitted to five doctors, five nurses, two patient educators, and two nurse instructors for screening. Any term that at least five members of the committee deemed highly technical was eliminated. Also deleted were terms that at least five members of the committee said that they did not normally use in speaking with patients. Of the 90 remaining terms, 50 were randomly selected and used in construction of the questionnaire. Byrne and Edeani demonstrated content validity of the tool but data on reliability were not obtained.

A pilot study was conducted by this researcher to test the tool for reliability and clarity. The pilot group
consisted of 10 persons who met the criteria for inclusion in the study except for the diagnosis of cancer. No one in the pilot group had a health care background. Some grammatical changes were made based on suggestions from the pilot group. To assess the stability of the tool, test-retest reliability was done. The group took the multiple choice test twice at 2 week intervals. The test-retest reliability coefficient was .96. The longest amount of time it took to complete the questionnaire was 30 minutes with most taking 15 minutes.

The tool consisted of 50 multiple choice questions concerning the definition of health care terms. Examples of questions were: (1) Your doctor tells you that you have a tumor. This means: (a) You have a rash (b) You have a lump that is cancerous (c) You have a lump that may or may not be cancerous; and (2) The nurse asks if you have constipation. This means: (a) You have bloody stools (b) You have watery stools (c) You have irregular and difficult stools. A subject’s score consisted of the number of correct answers. Those questions left blank were scored as no knowledge. A point was given for each correct answer with a possible range from 0 to 50.

Sample

The sample consisted of all 2,684 persons registered by the Oncology Data Service between 1985 and 1991. The
Oncology Data Service was started in 1977; approximately 1,800 new cases are added annually. The registry currently includes approximately 10,000 living persons of all ages who have been diagnosed with any type of cancer at some point in their lives. Each person remains on the registry list until death.

Criteria for inclusion in the study included: (1) age 20 years or older; (2) the ability to read and answer questions; (3) awareness of the diagnosis of cancer; and (4) registration with Oncology Data Services between 1985 and 1991. Those persons with in situ and benign/borderline cases were excluded.

Of the 2,684 persons in the sample, 1,676 responded, yielding a response rate of 62%. Of the 62%, 88% (1,476) of responses were usable. Twelve percent (193) of responses were unusable for a variety of reasons. Word was received from family members or the post office that 60 subjects had expired. Fifteen questionnaires were returned by persons less than 20 years of age; 33 persons who knew the potential subject wrote a note stating the subject was too ill to complete the questionnaire. Eleven subjects did not wish to complete the questionnaire. Sixty-three of the returned questionnaires had one or more pages incompletely answered. Two were completed by someone other than the subject. Eleven subjects claimed they did not have cancer and the
questionnaire was not used. Seven subjects returned the questionnaires after the correct responses were mailed.

Demographic Characteristics of the Sample

The demographic characteristics of the subjects are shown in Table 1. Females outnumbered males 869 (58.9%) to 587 (39.8%). Fifty-seven respondents (3.9%) were single, 1,071 (72.6%) were married, 246 (16.7%) were widowed and 73 (5%) were separated or divorced. One hundred thirty-six respondents (9.1%) had some grade school education, 790 respondents (53.5%) had some high school education, 459 respondents (31.12%) had some college education and 84 (5.7%) had an advanced degree. The mean educational level was 12.6 years. Ninety-two percent (1364) of the sample was White, 0.7% (10) was African American, 2% (29) was Native American and 0.9% (14) was categorized as other. Others included Hispanic Americans, Asian Americans, French and Italian. If the respondent circled more than one response such as White and Native American, the answer was scored as missing data. The ethnic origins of the sample were very homogeneous.

Sixty-one respondents (4.1%) had never had a hospitalization related to their cancer diagnosis, 1,191 respondents (80.7%) had been hospitalized one to five times, 109 respondents (7.4%) had been hospitalized six to ten times, 32 respondents (2.2%) had been hospitalized 11 to 15
Table 1  DEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE

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<th>VARIABLES</th>
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<td>1981-1982</td>
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<td>Before 1981</td>
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<tr>
<td><strong>SIZE OF COMMUNITY</strong></td>
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<tr>
<td>Less than 9,999</td>
<td>661</td>
<td>44.8</td>
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<tr>
<td>10,000-49,999</td>
<td>274</td>
<td>18.6</td>
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<tr>
<td>Greater than 50,000</td>
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<td>34.8</td>
</tr>
<tr>
<td>Missing</td>
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<td>1.9</td>
</tr>
<tr>
<td>Total</td>
<td>1476</td>
<td>100.1</td>
</tr>
</tbody>
</table>
times, 10 respondents (0.7%) had been hospitalized 16 to 20
times, 6 respondents (0.4%) had been hospitalized 21 to 25
times and 31 (2.1%) had been hospitalized 26 to 30 times.

Three hundred twenty-two respondents (21.8%) had health
professionals in their immediate family while 1,149 (77.8%)
did not. The age of persons with cancer ranged from 22 to 97
years with a mean age of 66. One hundred thirty-four of the
respondents (9.1%) had known of their cancer diagnosis less
than two years, 539 respondents (36.5%) had known of the
diagnosis for two to three years, 499 (33.8%) of the
respondents had known of the diagnosis for four to five
years, 43 respondents (2.9%) had known of the diagnosis for
six to seven years, 16 respondents (1.0%) had known of the
diagnosis for eight to nine years and 92 respondents (6.2%)
had known of their diagnosis for ten or more years.

Six hundred sixty-one respondents (44.8%) described the
size of the community in which they lived as less than 9,999,
274 respondents (18.6%) described the size of the community
in which they lived as 10,000 to 49,999, and 513 respondents
(34.8%) described the size of the community in which they
lived as greater than 50,000.

Rights of Human Subjects

Permission to conduct the study was granted by the
Drake University Human Subjects Committee and the Cancer
Committee at Iowa Methodist Medical Center (Appendix D). The rights of subjects were maintained. An introductory letter to each subject (Appendix E) specifically indicated the purpose of the study, the nature of participation, how anonymity would be preserved and of what consent consisted. The letter also indicated how to contact the researcher for questions and/or concerns, how to obtain results, and that a copy of correct answers would be sent to those who participated. The letter assured subjects that participation would not affect their health care in any way.

To recognize the possible decreased energy level of persons with cancer, the length of time to participate was limited to 30 minutes and the questionnaire could be completed in more than one sitting. The subjects were told what to expect in regard to time. The sensitivity of the questions was considered and one term excluded. The names selected were compared with a current list of death reports before the questionnaires were mailed.

Procedure

The questionnaire packet was mailed to the subjects in June 1991. The packet consisted of the introductory letter explaining the study, the two questionnaires and a stamped return envelope. Two weeks later, a thank you/reminder letter (Appendix F) was mailed to the subjects. Three weeks
after this, a final thank you letter (Appendix G) and correct answers were mailed to the subjects.

A code number in numerical order was assigned to each Informational Questionnaire and Health Care Terminology Questionnaire as it was returned. A computer spreadsheet indicated the code number, demographic responses, perceived level of knowledge of health care terminology and scores on the Health Care Terminology Questionnaire.
CHAPTER 4

RESULTS

The purpose of this study was to investigate the actual knowledge of health care terminology in persons with cancer. Perceived knowledge level of health care terminology, educational level, marital status, length of time of cancer diagnosis, number of hospitalizations, presence of health care professionals in the family, age, ethnic origin, sex and size of the community were the variables which were considered in analyzing data.

The range of correct responses on the Health Care Terminology Questionnaire was 20 to 50. The mean was 46.32, mode 49, and median 48. One hundred fifty-two respondents (10%) answered all 50 questions correctly. No question was answered correctly by all 1,476 respondents. The term surgeon had the highest number of correct responses, 1,475 (99.9%). The term with the second highest number of correct responses was enema, 1,474 (99.9%). The term radiation had the lowest number of correct responses, 539 (36.5%). The term with the second lowest number of correct response was emesis, 855 (57.9%). Thirty-eight of the 50 terms (76%) had a correct response rate of greater than 90%. See Appendix H for a complete listing of the correct, incorrect and no knowledge responses for each term.
One thousand one hundred fifty-five respondents had 90% of the 50 questions correct, 272 respondents had 80% of the questions correct, 46 respondents had 70% of the questions correct, 11 respondents had 60% of the questions correct and 6 respondents had less than 50% of the questions correct.

Hypotheses Testing

In order to test the hypotheses, the SAS computer package was used. An alpha level of .05 was established.

Hypothesis one stated: There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by perceived knowledge level. One hundred sixty-three respondents (11%) perceived themselves as very knowledgeable about health care terminology and had a mean correct score of 48.18; 1,114 respondents (75.5%) perceived themselves as fairly knowledgeable and had a mean correct score of 46.45; and 184 respondents (12.5%) perceived themselves as not knowledgeable and had a mean correct score of 44.29. There was a significant difference in the actual knowledge of health care terminology among the three groups, $F(2, 1458) = 59.85, p < .0001$ (Table 2).

The hypothesis was supported. Post hoc analysis using the Scheffé test indicated that those subjects who perceived themselves as very knowledgeable about health care
Table 2

<table>
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<tr>
<th>PERCEIVED KNOWLEDGE LEVEL</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
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<th>p</th>
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<tr>
<td>Within subjects</td>
<td>16280.11095</td>
<td>1458</td>
<td>11.16605</td>
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terminology had significantly higher scores than those who perceived themselves as fairly knowledgeable or not knowledgeable.

Hypothesis two stated: There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by educational level. There was a significant difference in actual knowledge of health care terminology among the four groups, \( F(3, 1465) = 65.64, p < .0001 \) (Table 3).

The hypothesis was supported. Post hoc analysis using the Scheffé test indicated that persons with 13 or more years of education scored significantly higher on the *Health Care Terminology Questionnaire* than those persons with 1 to 12 years of education. The mean correct score of those respondents with some grade school education was 43.17; the mean correct score of those with some high school education
Table 3

<table>
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<th></th>
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<tr>
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<td>15541.82481</td>
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<td>65.64</td>
<td>.0001</td>
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</table>

was 46.20; the mean correct score of those with some college education was 47.24 and for those respondents with an advanced degree the mean correct score was 48.27.

Hypothesis three stated: There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by marital status. There was a significant difference in actual knowledge of health care terminology among the four groups, $F(3, 1443) = 3.85$, $p < .0093$ (Table 4).

The hypothesis was supported. Post hoc analysis by the Tukey test indicated that married subjects scored significantly higher than widowed subjects. The mean correct score of those respondents who were single was 45.53; the mean correct score of those who were married was 46.53; the mean correct score of those who were widowed was 45.87 and the mean correct score of those who were divorced/separated
Hypothesis four stated: There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by length of cancer diagnosis. There was no significant difference in knowledge of health care terminology among the six groups, $F(5, 1317) = 1.70$, $p < .1313$ (Table 5).

The hypothesis was not supported. The mean correct score of those respondents who were diagnosed with cancer in 1989 to 1991 was 46.09; those diagnosed in 1987 to 1988 had a mean correct score of 46.63; those diagnosed in 1985 to 1986 had a mean correct score of 46.32; those diagnosed in 1983 to 1984 had a mean correct score of 46.40; those diagnosed in 1981 to 1982 had a mean correct score of 46.25 and those who were diagnosed prior to 1981 had a mean correct score of 47.16.
Table 5  

<table>
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Hypothesis five stated: There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by number of hospitalizations. There was no significant difference in actual knowledge of health care terminology among the seven groups, $F(6, 1433) = 1.25, p < .2801$ (Table 6).

The hypothesis was not supported. The mean correct score of those respondents with no hospitalizations relating to their cancer diagnosis was 46.80; those respondents with one to five hospitalizations had a mean correct score of 46.38; those respondents with six to ten hospitalizations had a mean correct score of 46.87; those respondents with 11 to 15 hospitalizations had a mean correct score of 46.09; those with 16 to 20 hospitalizations had a mean correct score of 46.10; those with 21 to 25 hospitalizations had a mean correct score of 46.17 and a mean correct score of 45.13 was
Table 6

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</table>

demonstrated for those respondents with 26 to 30 hospitalizations.

Hypothesis six stated: There will be a significant difference in actual knowledge of health care terminology when the subjects are categorized by the presence or absence of health care professionals in the subject's immediate family. Significant differences in the knowledge of health care terminology were found between those who had health care professionals in their family and those who did not, \( t(1469) = 4.886, p < .0001 \) (Table 7).

The hypothesis was supported. The mean correct score of those who had health care professionals in their family was 47.15 and the mean correct score for those who did not was 46.12.

Hypothesis seven stated: There will be a significant difference in actual knowledge of health care terminology
Table 7 HEALTH CARE PROFESSIONALS IN FAMILY

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
<th>df</th>
<th>t</th>
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<tbody>
<tr>
<td>n</td>
<td>322</td>
<td>1149</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>M</td>
<td>47.15</td>
<td>46.12</td>
<td>1469</td>
<td>4.886</td>
<td>.0001</td>
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<tr>
<td>SD</td>
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<td>3.50</td>
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</tbody>
</table>

when the subjects are categorized by age. Significant differences were found in actual knowledge of health care terminology among the eight groups, $F(7, 1377) = 8.26, p < .0001$ (Table 8).

The hypothesis was supported. Post hoc analysis using the Scheffé test indicated that subjects in the 40 to 49 age group scored significantly higher than subjects in the 70 to 79 and 80 to 89 age groups. Post hoc analysis also indicated that subjects in the 50 to 59 and 60 to 69 age groups scored significantly higher than subjects in the 80 to 89 age group. The highest mean correct score, 47.48, was in the 40 to 49 age group; the second highest mean correct score, 46.83, was in the 60 to 69 age group; the lowest mean correct score, 44.00, was in the 90 to 99 age group and the second lowest mean correct score, 44.93, was in the 20 to 29 age group.

Hypothesis eight stated: There will be a significant difference in actual knowledge of health care terminology
Table 8

<table>
<thead>
<tr>
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<th>df</th>
<th>MS</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
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<tr>
<td>Between subjects</td>
<td>650.344532</td>
<td>7</td>
<td>92.90636</td>
<td>8.26</td>
<td>.0001</td>
</tr>
<tr>
<td>Within subjects</td>
<td>15493.99481</td>
<td>1377</td>
<td>11.25199</td>
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</tr>
</tbody>
</table>

when the subjects are categorized by ethnic origin.
Significant differences were found in actual knowledge of health care terminology among the four groups, $F(3, 1413) = 2.96, p < .0312$ (Table 9).

Table 9

<table>
<thead>
<tr>
<th></th>
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<th>F</th>
<th>p</th>
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<tbody>
<tr>
<td>Between subjects</td>
<td>101.959312</td>
<td>3</td>
<td>33.98643</td>
<td>2.96</td>
<td>.0312</td>
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<td>16211.52692</td>
<td>1413</td>
<td>11.47312</td>
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</tbody>
</table>

The hypothesis was supported. Post hoc analysis using the Tukey test indicated that White respondents scored significantly higher than Native American respondents. The
mean correct score for those respondents of White ethnic origin was 46.46; the mean correct score for African Americans was 45.30; the mean correct score for Native Americans was 44.79 and 45.57 was the mean correct score for respondents of other ethnic origins.

Hypothesis nine stated: There will be no difference in actual knowledge of health care terminology when the subjects are categorized by sex. Significant differences in the knowledge of health care terminology were found between the males and females, \( t(1454) = 5.178, p < .0001 \) (Table 10).

<table>
<thead>
<tr>
<th>Table 10</th>
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<tr>
<td>MALES</td>
<td>FEMALES</td>
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<tr>
<td>n=587</td>
<td>n=869</td>
</tr>
<tr>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>45.78</td>
<td>3.75</td>
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</tbody>
</table>

The hypothesis was not supported. Women scored significantly higher than men on the Health Care Terminology Questionnaire. The mean correct score for males was 45.78 and the mean correct score for females was 46.76.

Hypothesis ten stated: There will be no difference in actual knowledge of health care terminology when the subjects are categorized by the size of their community. Significant
differences in the knowledge of health care terminology were found among the three groups, $F(2, 1445) = 6.40, p < .0017$ (Table 11).

Table 11

<table>
<thead>
<tr>
<th></th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between subjects</td>
<td>151.46294</td>
<td>2</td>
<td>75.73147</td>
<td>6.40</td>
<td>.0017</td>
</tr>
<tr>
<td>Within subjects</td>
<td>17086.16136</td>
<td>1445</td>
<td>11.82433</td>
<td></td>
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</tr>
</tbody>
</table>

The hypothesis was not supported. Post hoc analysis using the Scheffé test indicated a significant difference between those respondents from communities with less than 9,999 people and those from communities with greater than 50,000 people. The mean correct score of respondents from a community with less than 9,999 people was 46.11; the mean correct score of respondents from a community with 10,000 to 49,999 people was 46.22 and the mean correct score of those respondents from a community with greater than 50,000 people was 46.81.
CHAPTER 5

DISCUSSION OF RESULTS

The purpose of this study was to investigate the actual knowledge of health care terminology in persons with cancer. Perceived knowledge level of health care terminology, educational level, marital status, length of time of cancer diagnosis, number of hospitalizations, presence of health care professionals in the family, age, ethnic origin, sex and size of the community were variables considered in analyzing data. In this chapter, a discussion of the findings, implications of these findings for nursing, limitations of the study and recommendations for further research on the knowledge of health care terminology are found. The chapter concludes with a summary of the study.

Discussion of Findings

Findings of this study are discussed as they relate to Orem's (1991) Self-Care Deficit Model. The findings are then compared to other studies.

Orem's Self-Care Deficit Model

These findings have implications for those who use Orem's (1991) Self-Care Deficit Model. Orem believed that a patient requires knowledge in order to provide self-care. Although this study did not examine self-care practices, a
lack of knowledge could deter a person from performing self-care. Orem also believed there are limitations of knowledge that contribute to self-care deficits. Lack of understanding of health care terminology is a limitation of knowledge. While 78% of the respondents answered 90% of the questions correctly, the nurse must be aware of the 22% who lack knowledge of health care terminology.

Self-care agency is the individual's capabilities and actions for self-care (Orem, 1991). Those with more knowledge possibly have a stronger self-care agency. Orem believed self-care is used for self-maintenance and self-regulation. One form of regulation is the health-deviation requisite which arises from or is associated with a person's health state and associated health care. The health-deviation requisite for persons in this study was dealing with their cancer diagnosis. In order to deal with their diagnosis, persons with cancer must learn about proper nutrition, how to avoid infection, how to avoid stress and how to maintain a positive attitude. Orem also believed that if a person is to manage health-deviation self-care, they must also be able to apply relevant medical knowledge to their own care.

Comparisons with Other Studies

The study of Byrne and Edeani (1984), which was
partially replicated, investigated relationships among knowledge of health care terminology and the variables of sex, age, educational level, perceived knowledge level, length of illness and number of hospitalizations. The sample in this study consisted of only persons with cancer and the sample was larger (1476 compared to 125) than in the study by Byrne and Edeani. In this study, 152 respondents (10%) answered all 50 questions correctly while no respondent answered all 50 questions correctly in the study by Byrne and Edeani. As with the study by Byrne and Edeani, no question was answered correctly by all respondents. In the study by Byrne and Edeani, the scores ranged from 4 to 48 with a mean of 36. In this study the scores ranged from 20 to 50 with a mean of 46. In the study by Byrne and Edeani, 12 terms had correct response rates of greater than 90%. In this study, 38 terms had correct response rates of greater than 90%. Of those 12 terms, 11 were included in the greater than 90% correct response rate of this study. The 12th term, autopsy, was removed due to the sensitivity of the term to persons with cancer.

It was hypothesized that there would be a significant difference in actual knowledge of health care terminology when the subjects were categorized by perceived knowledge level. The findings in this study were similar to those reported by Byrne and Edeani (1984). Both studies found a
significant relationship between the variable of perceived knowledge level and correct scores. In the study by Byrne and Edeani, 66% of respondents rated themselves as fairly knowledgeable, while 75.5% did so in this study. In the study by Byrne and Edeani, 24% of respondents rated themselves as very knowledgeable, while 11% did so in this study. Ten percent rated themselves as not knowledgeable in the study by Byrne and Edeani, while 12.5% did so in this study. In the study by Byrne and Edeani, the more the respondents felt they knew the more they actually did know. The results of this study also indicated that those who perceived themselves as very knowledgeable scored significantly higher than those who perceived themselves as fairly or not knowledgeable. The findings may suggest that those persons who rated themselves as very knowledgeable had prior experiences with health care professionals which reinforced their learning. It is also possible that those who rated themselves as very knowledgeable may also have had higher educational levels. Perhaps those respondents possessed more self-care agency and were interested in understanding as much as possible about their illness.

It was hypothesized that there would be a significant difference in actual knowledge of health care terminology when the subjects were categorized by educational level. The findings of this study were similar to the findings of Byrne
& Edeani (1984); Gibbs, et al. (1987); Samora, et al. (1961); Shaughnessy (1988); Smeltzer (1980) and Spiro & Heidrich (1983). In these studies, respondents with a higher educational level had a higher score on various tests of health care terminology. In the study by Byrne and Edeani, as educational level increased scores increased. In this study, respondents with 13 or more years of education scored significantly higher than those with 1 to 12 years of education. The mean correct scores have improved in the eleven years between this study and the study by Byrne and Edeani. The mean correct score for those with some grade school education was 23 in the study by Byrne and Edeani and 43.17 in this study. The mean correct score for those with some high school education was 38.3 in the study by Byrne and Edeani and 46.20 in this study. The mean correct score for those respondents with some college education was 40.2 in the study by Byrne and Edeani and 47.24 in this study. The mean correct score for those respondents with advanced degrees was 42 in the study by Byrne and Edeani and 48.27 in this study. Perhaps those respondents with more education possess a broader repertoire of knowledge.

It was hypothesized that there would be a significant difference in the actual knowledge of health care terminology when the subjects were categorized by marital status. None of the other studies used the variable of marital status when
examining knowledge of health care terminology. In this study, there was a significant difference between marital status and correct scores with married respondents scoring significantly higher than widowed respondents. The findings suggest that married respondents share information about their health status with their spouse and are exposed to different health care terms. Perhaps married respondents received help with the questionnaire that was not available to widowed respondents.

It was hypothesized that there would be a significant difference in the actual knowledge of health care terminology when the subjects were categorized by length of diagnosis. The findings of this study were similar to the findings of Byrne and Edeani (1984) and Smeltzer (1980). No significant difference or relationship was supported between correct scores and the length of diagnosis of the respondents' disease. Perhaps respondents who have lived longer with the diagnosis of cancer have had more stress that inhibited learning health care terminology. It is also possible that if the diagnosis was made long enough ago and the person has been healthy for a number of years, the learned terminology may have been forgotten.

It was hypothesized that there would be a significant difference in the actual knowledge of health care terminology when the subjects were categorized by number of
hospitalizations. The findings of this study were similar to findings by Byrne and Edeani (1984) and Smeltzer (1980). No significant difference or relationship was supported between correct scores and the number of hospitalizations. Smeltzer (1980) was only interested in hospitalizations in the past year. Possibly the findings indicate that persons who are hospitalized may not have learned health care terminology due to the stress of being hospitalized and acutely ill. Perhaps health care professionals assume those clients with more frequent hospitalizations have more knowledge of health care terminology than they actually do and do not explain the terminology used in their care.

It was hypothesized that there would be a significant difference in the actual knowledge of health care terminology when the subjects were categorized by the presence or absence of health care professionals in the immediate family, a variable other studies did not examine. Those respondents with health care professionals in their immediate family scored significantly higher than those who did not have health care professionals in their immediate family. The findings may suggest that respondents with health care professionals in their immediate family were exposed to more health care terminology and had opportunities to ask the meaning of terms without feeling embarrassed. Those without health care professionals in their family possibly did not
have the opportunity to ask questions or listen to health care professionals discuss their careers.

It was hypothesized that there would be a significant difference in the actual knowledge of health care terminology when the subjects were categorized by age. The findings of this study were similar to the findings of Byrne and Edeani (1984), Shaughnessy (1988) and Smeltzer (1980), all reporting significant differences between age and correct scores on various tests regarding health care terminology. The study by Smeltzer demonstrated that age was a predictor only in defining medical terminology, not common terminology related to hypertension. Smeltzer found that respondents aged 40 to 49 correctly answered half of the questions. This study found that respondents in the 40 to 49 age group answered 95% of questions correctly. This demonstrates an improvement in knowledge in this age group in the last 11 years.

This study used post hoc analyses to determine that subjects in the 40 to 49 age group scored significantly higher than subjects in the 70 to 79 and 80 to 89 age group. Post hoc analyses also indicated that subjects in the 50 to 59 and 60 to 69 age groups scored significantly higher than subjects in the 80 to 89 age group. Shaughnessy (1988) only demonstrated significant differences between correct scores in the youngest and oldest age groups. In the study by Byrne and Edeani (1984), the highest scores were found in persons
in the 31 to 70 age bracket, the lowest scores in the 71+ and under 30 age brackets.

Findings from this study differed from those of Gibbs, et al. (1987), Samora, et al. (1961) and Spiro and Heidrich (1983) who reported no significant difference or relationship between correct scores and age. Perhaps those respondents of the middle age groups are living during a time when health care professionals explain more health care terminology to them than persons of older age groups. Perhaps some health care professionals are under the false assumption that the elderly cannot learn.

It was hypothesized that there would be a significant difference in actual knowledge of health care terminology when the subjects were categorized by ethnic origin. The findings of this study were similar to the findings of Shaughnessy (1988), Samora, et al. (1961) and Smeltzer (1980). Shaughnessy and Smeltzer reported significant differences between knowledge level and ethnic origin with White respondents scoring higher than African American respondents. Samora, et al. reported that White respondents scored significantly higher than Hispanic American respondents. In this study, White respondents scored significantly higher than Native American respondents.

Findings in this study differed from those of Gibbs, et al. (1987) who reported no significant difference between
correct score and ethnic origin. Perhaps White Americans have more access to health care and health care professionals than Native American respondents. There may also be language barriers that account for the lack of understanding of health care terminology among Native Americans.

It was hypothesized that there would be no significant difference in actual knowledge of health care terminology when the subjects were categorized by sex. In this study as in that by Shaughnessy (1988), women scored significantly higher than men on a test of health care terminology. The findings differed from those of Byrne and Edeani (1984), Gibbs, et al. (1987), Samora, et al. (1961) and Spiro and Heidrich (1983) who reported no significant difference or relationship between sex and knowledge level. The difference in findings regarding sex may be related to the large sample in this study. Women may also spend more time discussing their health care with other women. Men may not be as likely to discuss their health care with other men. There seems to be more discussion of women's health concerns in the media (e.g. self breast exam and annual papanicolaou smears) than there is of men's health concerns.

It was hypothesized that there would be no significant difference in actual knowledge of health care terminology when the subjects were categorized by the size of the community in which they lived. While significant findings
were not expected, those who lived in a community with greater than 50,000 people scored significantly higher than those respondents who lived in a community with less than 9,999 people. The findings suggest that those respondents living in larger communities have increased exposure to health care terminology because they are closer to health care facilities and health care professionals. Those living in larger communities have opportunities to interact with more people with differing backgrounds and health care experiences.

Implications for Nursing

Orem (1991) believed self-care agency is the individual's capabilities and actions for self-care. Orem also believed a therapeutic self-care demand is the demand an individual faces for the capabilities and actions to meet self-care requisites. When the self-care agency is insufficient to meet the therapeutic self-care demand, a self-care deficit is present. When a nurse cares for clients, the nurse assesses self-care deficits. A nurse must also assess the client's self-care agency and therapeutic self-care demand to determine where the deficit exists. Since Orem believed a client needs knowledge in order to perform self-care, a lack of understanding of health care terminology could contribute to a self-care deficit. Nurses
need to do a complete health assessment in order to determine nursing interventions.

Orem's (1991) supportive-educative system is applied to situations in which the person needs to perform self-care measures but requires help with decision making, behavior control and acquiring knowledge and skills. Once a nurse assesses a person's knowledge of health care terminology, the nurse and patient can set goals in order to meet the self-care deficit. The nurse also must consider the health-deviation requisite the client is dealing with in order to determine a plan of action. Persons with cancer need to understand the importance of proper nutrition, avoiding infection and the side effects of the therapy they are undergoing.

Nurses must be cautious in using the findings of this study. While the findings indicate there are statistical differences among certain variables (men and women, married and widowed, higher and lower educational levels, those who perceive themselves to be more knowledgeable, those aged 40 to 69, those with health care professionals in their family, White and Native American and those living in a community with greater than 50,000 people), the mean score for each group were close. The statistically significant differences could be related to the large sample size. Nurses could use these variables as part of their nursing assessment for self-
care deficits. Nurses also need to assess clients for their knowledge level as part of the teaching learning process. A client's knowledge level and demographic variables may be important. Byrne and Edeani (1984) cautioned that while a patient's level of knowledge cannot be determined solely by self-evaluation, the patient educator will have a more complete assessment if a self-report of knowledge level is used. Since the findings of this study were similar to those of Byrne and Edeani, nurses could cautiously use a client's perceived knowledge level as part of their assessment. If a client perceived a lack of knowledge of health care terminology, the nurse should assess the client further and be prepared to explain the terminology used in speaking with the client.

There has been an increased focus on health in this country in the past ten years. There is more discussion of health related matters in the media as well as an increased awareness of cancer. Cancer is no longer a taboo subject and public figures with cancer, such as former President and Nancy Reagan, Marilyn Quayle, Ann Jillian and H.R. Bloch are telling their stories. In addition to increasing awareness, more people are following cancer screening guidelines. The mean scores from this study were higher than in the study by Byrne and Edeani (1984) conducted 11 years ago. This may be related to the increased focus on health and persons taking
more responsibility for their health. Perhaps health care professionals have been assessing a client's knowledge of health care terminology and communicating with clients based on those assessments. The sample in this study had lived in or spent time in Iowa. The state of Iowa does have a high literacy rate. Persons with cancer receive health care from specialist physicians and specialty nurses and perhaps more time and effort are spent assuring that clients understand health care terms used in their care.

While a majority of the sample had a high knowledge level of health care terminology, nurses must not become complacent and assume that the knowledge level of everyone has improved. Nurses need to focus on those with a limited knowledge level and improve assessment techniques in order to determine which clients have less understanding. As health care becomes more complex, clients will need to learn new, more specific terminology related to health or their disease process. This has further implications for nurses.

Nurses play an important role in patient education. Nurses not only need to assess clients but need to plan educational experiences based on those assessments and obtain feedback to determine if learning has occurred. It is essential that a client understand health care terminology if patient education is to be effective. Patient education which is not effective can adversely affect clients' health
and possibly their level of compliance. Poor communication between clients and health care professionals can leave clients dissatisfied with their care and the health care institution.

Nurses need to continue to find ways to help clients become more familiar with health care terminology. Clients could be helped by a handbook of health care terminology that may be used in an outpatient or inpatient setting. The most important way is to increase awareness among all health care professionals that they may be using terms that are not understood. New terminology needs to be introduced through simple explanations. As discussed by Bourhis, et al. (1989), the nurse is often the "communication broker" between physicians and patients. Nurses should continue in this role to help clients understand health care terminology.

There are further implications for nursing based on the results of this study. Perhaps elderly clients have less knowledge of health care terminology because health care professionals are following the false assumption that the elderly cannot learn. The sensory deficits in hearing and vision perhaps contribute to the lack of knowledge of health care terminology. Nurses need to assess for and help modify any sensory deficits and be careful when using health care terminology with older persons.

The educational level of the client must be considered
when using health care terminology with clients. It is possible that those clients with more education have a greater knowledge of health care terminology. Nurses must also assess for preferred learning style, sensory deficits and literacy of each client.

Perhaps nurses assume those clients who are frequently hospitalized or have a longer length of diagnosis of cancer have more knowledge of health care terminology because of increased contact with the health care system. Nurses need to assess their clients thoroughly before assuming they understand the health care terms used in their care.

Nurses must consider the ethnic diversity and possible language barriers of clients when using health care terminology. Nurses must be aware of the different ethnic groups in the community and what support services, such as interpreters, are available.

Since most nurses are women, perhaps women communicate easier with women. Women clients may be less intimidated about asking questions about health care terminology when their nurses are women. Perhaps nurses need to open communication with men clients and not assume that because there are no questions that men understand the health care terminology used in their care.

Nurses should assess for the presence or absence of health care professionals in the client’s family and perhaps
continue to incorporate family members into patient education to reinforce the clients learning of health care terminology. Nurses also should assess for a client's marital status and if the client is widowed assess for significant others from which the client receives support. These support persons can be included in patient education. A person who lives alone has less opportunity to validate health information. Perhaps nurses need to include widowed clients in group patient education experiences or support groups so health information can be shared which may increase knowledge of health care terminology.

Nurses should consider the size of the community in which their clients reside when using health care terminology. Smaller communities do not have as many nurses and doctors available as in larger communities. Nurses should consider ways to increase clients exposure to health care terminology. The clients may benefit from group patient education (e.g. I Can Cope) and support groups. The county nurses could have an increased role in this area. Nurses from larger communities may provide patient education programs to clients in smaller communities.

Limitations of the Study

A number of limitations are present in this study. Caution should be used in generalizing the results to other
persons with cancer or to any other client populations.

There are factors that could have affected the results of this study. The sample of terms is not inclusive of all terminology heard by clients. When the sample was selected, the benign/borderline and in situ cases were inadvertently included. This mistake was discovered three days after the questionnaires were mailed to the sample. Some of the questionnaires were mailed on a Friday and on Monday the mistake was discovered. When the mistake was discovered, a letter was sent to those subjects asking them to disregard the questionnaire. Phone calls were made to as many subjects as possible and many had not yet received the questionnaires. Therefore, it is not known if any of these 347 questionnaires were included in the findings. If respondents claimed they did not have cancer, their returned questionnaire was omitted.

The subjects were asked not to use a dictionary or ask for help when completing the questionnaire. Since the questionnaires were mailed to the subjects' homes, this researcher was unable to be certain that the subjects honored this request. Also since the subjects completed the questionnaires at home, they may have been under the influence of medications that may have affected their thought processes (e.g. analgesics and antiemetics).

The responses to the question about ethnic origin may
have affected the results of the hypothesis measuring differences between correct scores and ethnic origin. Several respondents circled both White and Native American and 27 respondents circled only Native American. If the respondent circled both White and Native American the answer was scored as missing data. If the respondent circled only Native American the answer was scored as such. It is possible that those respondents who circled Native American did not know that it was synonymous with American Indian and meant to circle White as their ethnic origin. If this was the case, the findings may not have demonstrated a significant difference between White respondents and Native American respondents.

In retrospect, the answers to the terms radiation and abdomen could have been clarified. This may have affected the correct responses for these terms. Only 36.5% answered the term radiation correctly and 79.3% answered the term abdomen correctly.

Recommendations for Future Research

In this study, there were significant differences between actual knowledge of health care terminology and the variables of sex, marital status, educational level, ethnic origin, the presence of health care professionals in the family, age, perceived knowledge level and size of the
community. Recommendations for further study include the following:

1. A replication of this study with a different client population and further statistical tests to determine which combination of variables affect knowledge.

2. An investigation of clients' knowledge of less common and more technical health care terminology such as white blood count, neutrophil, sodium, potassium, melanoma and Adriamycin.

3. An investigation of the following questions: Do those clients with a higher knowledge level of health care terminology have shorter hospital stays, longer time periods out of the hospital and obtain prompt treatment of new problems? Do those clients with a higher knowledge level of health care terminology have increased satisfaction with their health care? Do those clients with a higher knowledge level of health care terminology comply more with medication and treatment regimens?


Summary

The sample was comprised of 2,684 persons with a diagnosis of cancer. Criteria for inclusion in the study
included: (1) age 20 years or older; (2) the ability to read and answer questions; (3) awareness of the diagnosis of cancer and (4) registration with Oncology Data Services between 1985 and 1991. A questionnaire packet consisting of the Informational Questionnaire, the Health Care Terminology Questionnaire and an introductory letter explaining the study was mailed to the subjects' homes. The subjects were asked to complete the two questionnaires without help from a dictionary or significant other. The subjects were also asked to respond with a note explaining why they could not complete the questionnaires if they were unable to do so. The possible range of scores was 0 to 50. There was a significant difference among correct scores and sex, marital status, educational level, ethnic origin, perceived knowledge level, the presence of health care professionals in the immediate family, age and size of the respondent's community. There were no significant differences between correct scores and length of diagnosis and number of hospitalizations. In assessing learning needs of persons with cancer, knowledge of health care terminology and variables which might influence such knowledge are vital for a thorough assessment.
References


Appendix A

Informational Questionnaire
Please answer this questionnaire first.

INFORMATIONAL QUESTIONNAIRE

Please circle the information about yourself. Try to be as specific as possible.

Sex: (1) Male (2) Female

Marital Status: (1) Single (2) Married (3) Widowed (4) Divorced (5) Separated

Education: Circle the highest grade completed.

Grade School: (1) First (2) Second (3) Third (4) Fourth (5) Fifth (6) Sixth (7) Seventh (8) Eighth

High School: (1) Freshman (2) Sophomore (3) Junior (4) Senior

College: (1) Freshman (2) Sophomore (3) Junior (4) Senior

Do you have an advanced degree (Masters or Doctorate)? (1) yes (2) no

Ethnic Origin: (1) White (2) African American (3) Hispanic American (4) Asian American (5) Native American (6) Other__________

How many times have you been hospitalized for cancer including treatments and side effects?

(1) 1-5 hospitalizations
(2) 6-10 hospitalizations
(3) 11-15 hospitalizations
(4) 16-20 hospitalizations
(5) 21-25 hospitalizations
(6) 26-30 hospitalizations

Do you have any health care professionals (example: doctors, nurses, pharmacists, or physical therapists) in your immediate family (mother, father, brother, sister, children)?

(1) yes (2) no

How knowledgeable are you of the health care terms frequently used by doctors and nurses?

(1) Very knowledgeable
(2) Fairly knowledgeable
(3) Not knowledgeable

In what size community do you live?

(1) Less than 500 people
(2) 501 - 3,999 people
(3) 4,000 - 9,999 people
(4) 10,000 - 19,999 people
(5) 20,000 - 49,999 people
(6) More than 50,000 people

(over)
Please fill in the information about yourself.

Your age on your last birthday: 

When were you diagnosed with cancer? 

Month

Year

________________________________________

________________________________________
Appendix B

Health Care Terminology Questionnaire
Please answer this questionnaire after you have completed the Informational Questionnaire.

**HEALTH CARE TERMINOLOGY QUESTIONNAIRE**

Please circle the one statement that best describes the meaning of the underlined word. Rather than guessing, leave questions you are unsure about blank. Do not ask for help from friends or family; please do not look words up in the dictionary.

1. The **abdomen** is the part of the body:
   (a) Between the chest and hips
   (b) Between the waist and knees
   (c) Between the head and chest

2. Your doctor tells you that you have a **tumor**. This means:
   (a) You have a rash
   (b) You have a lump that is cancerous
   (c) You have a lump that may or may not be cancerous

3. Your nurse asks if you have **voided**. This means:
   (a) Have you urinated?
   (b) Have you vomited?
   (c) Have you passed gas?

4. **Cholesterol** is found in:
   (a) Foods like eggs, butter and oils
   (b) Vegetables like lettuce and cabbage
   (c) The water we drink

5. The nurse asks if you have **constipation**. This means:
   (a) You have bloody stools
   (b) You have watery stools
   (c) You have irregular and difficult stools

6. Your doctor says that you have **hypertension**. This means:
   (a) You have gallbladder problems
   (b) You have high blood pressure
   (c) You have heart problems

(over)
7. To say that someone has expired means:
   (a) The person has died
   (b) The person was admitted to the hospital
   (c) Your person was released from the hospital

8. When your pain radiates it means:
   (a) Your pain has stopped
   (b) Your pain extends from one part of the body to another part
   (c) Your pain has gotten worse

9. Every morning the nurse asks if you have had a bowel movement. This means:
   (a) Did you turn over in your bed?
   (b) Did you have a good night sleep?
   (c) Did you pass any stool?

10. *Diabetes Mellitus* is a disease that causes:
    (a) Sugar to be passed in the urine
    (b) Blood to be passed in the urine
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    (a) You have no lungs
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    (c) Your lungs contain a large amount of some liquid

12. A terminal illness means:
    (a) The illness will inevitably cause death
    (b) The illness can be cured
    (c) No illness was found in the body

13. *Metastasis* refers to:
    (a) An examination of the body during an operation
    (b) Cancer spreading within the body
    (c) A breast being removed
14. When you tell the nurse that you are **allergic** to a medication, you are saying:
   
   (a) Your body has a sensitive reaction to the medicine  
   (b) Your body tolerates any medicine  
   (c) You take some type of medication at home

15. The nurse says that the **resident** will be here to see you. A **resident** is:
   
   (a) A doctor who works in the hospital while training  
   (b) Another patient who has the same illness as you  
   (c) A specialist doctor

16. When you told the doctor that you had **numbness** in your hands, you meant:
   
   (a) You have swelling of both hands  
   (b) You have pain in both hands  
   (c) You do not have any feeling in your hands

17. Your doctor asks if you were having **palpitations**. This means:
   
   (a) Your heart beat is very slow  
   (b) Your heart beat is fast, hard and irregular  
   (c) Your heart beat often stops and starts again

18. **Amputation** means:
   
   (a) To have an operation  
   (b) To transplant a part of the body  
   (c) To remove a diseased part of the body by an operation

19. The doctor told a woman that she will have a **mastectomy**. This means:
   
   (a) She will have a stone removed from her gallbladder  
   (b) She will have a breast removed  
   (c) She will have a test to examine her breast

20. The **coronary care unit** is the part of the hospital:
   
   (a) Where patients with heart problems are cared for  
   (b) Where patients with broken bones are cared for  
   (c) Where operations are done

(over)
21. An **EKG** is a test done to determine how:
   (a) Your eyes are working
   (b) Your heart is working
   (c) Your blood is working

22. Your dietitian says you must avoid **carbohydrates**. **Carbohydrates** are:
   (a) Starchy foods like potatoes, bread, and sugars
   (b) Meats like beef and lamb
   (c) Vegetables like lettuce and spinach

23. Your x-rays show that you have a **gastric ulcer**. This means a:
   (a) Sore in your mouth
   (b) Sore in your stomach
   (c) Sore in your throat

24. The doctor wants you to get help at home because you need a long **convalescent** period. This refers to the:
   (a) Period before you got sick
   (b) Period after you have recovered from your illness
   (c) Period while you are recovering from your illness

25. The **symptoms** of a disease are:
   (a) Any change in your normal body pattern
   (b) Only those changes the doctor or nurse asked for
   (c) Any medicine that you may have taken

26. The nurse tells you that you need to be **catheterized**. This means:
   (a) A tube is put into your bladder to remove urine
   (b) A tube is put into your stomach
   (c) An x-ray is taken of your chest

27. A **complication** of an illness is:
   (a) Another illness added to the first illness
   (b) The first illness that made you go to a doctor
   (c) Getting better from an illness without seeing a doctor
28. The doctor has not made a diagnosis of your illness. This means:

(a) Your illness cannot be cured
(b) Your illness has been cured
(c) Your doctor has not determined the name of your illness

29. A medicine to be taken orally is:

(a) To be taken by shots
(b) To be taken by mouth
(c) To be rubbed on the skin

30. Your friend was told that he has angina. This means he has:

(a) A heart attack
(b) Pain in his kidneys
(c) Occasional pain in the chest around the heart

31. A patient who has a colostomy has:

(a) An infectious illness that other people may catch
(b) An illness which he will die from
(c) An opening in the belly for passing stool

32. If someone’s blood test is abnormal, this means:

(a) The test was not done
(b) The result of the test was unusual
(c) The result of the test will be known later

33. The nurse monitors Intake and Output. This means:

(a) All the liquid you drink and the liquid you pass should be measured
(b) All your activities should be watched
(c) All your visitors should be restricted

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(a) The person has cancer of the lung
(b) The person has an unusual spot in the lung which may or may not be cancer
(c) The person needs to have a bath

(over)
35. When the nurse says that you will get an enema, you expect the nurse to put plain water or water with medicine in your:
   (a) Rectum
   (b) Mouth
   (c) Ears

36. Your doctor said a surgeon will see you. You should expect:
   (a) A special nurse
   (b) A doctor who works in the x-ray department
   (c) A doctor who specializes in doing operations

37. The nurse asks if you are nauseated. This asks:
   (a) Are you thirsty?
   (b) Are you sick to your stomach?
   (c) Are you hungry?

38. If you are going to get an injection, you should expect:
   (a) A shot
   (b) A pill
   (c) An enema

39. The doctor told you to get your prescription from the nurse. You expect to get:
   (a) A written order for medicine signed by the doctor
   (b) An instruction for your activity at home
   (c) A bottle of pills

40. You are asked to bring a specimen of your urine to the clinic. This means you should:
   (a) Bring all your urine
   (b) Bring no urine but tell the nurse what your urine looks like
   (c) Bring part of your urine

41. When you are given a suppository to take at home, this medicine must be taken:
   (a) By mouth only
   (b) By rectum
   (c) By melting it and rubbing it on your skin
42. The nurse asks if you have had any **emesis**. This asks:
   
   (a) If you have urinated  
   (b) If you have eaten  
   (c) If you have vomited  

43. The doctor gave you an order for some pills to help reduce **edema** in your legs. This means:
   
   (a) Swelling due to collection of fluid in your legs  
   (b) Pain in your legs  
   (c) Rashes on your legs  

44. If you are to get **intravenous** feeding you can expect:
   
   (a) A cup of some liquid to drink  
   (b) A shot in your buttock  
   (c) A needle in your arm to run some liquid into your body  

45. Your roommate is going to have a **biopsy** of the liver. This means:
   
   (a) He is going to have blood drawn from his liver  
   (b) He is going to have an examination of his liver during an operation  
   (c) He is going to have a small piece of the liver removed for testing  

46. A doctor walks into your room and tells you that he/she is here on **consultation** to see you. This doctor is probably:
   
   (a) A specialist acting on an advisory basis to your doctor  
   (b) A medical student who needs practice  
   (c) A new doctor taking over your care  

47. You can only get **radiation** if you:
   
   (a) Are being treated for any type of cancer  
   (b) Have broken bones  
   (c) Go near any radioactive material  

48. The **dietitian** will give you instructions about:
   
   (a) Your medicine and how to take it  
   (b) Your food  
   (c) Any part of your body that is painful
49. Your nurse asks if you have a prosthesis. This asks for:

(a) Any part of your body that is artificial
(b) Artificial legs or hands only
(c) Any part of your body that is painful

50. There is a sign at your bedside that states you are NPO. This means:

(a) You are to have nothing to eat or drink by mouth
(b) You are on bedrest
(c) You are to have no visitors

Thanks!!!!!!
Appendix C

Permission to Use Tool
October 4, 1989

Kim Turner
1547 47th Street
Demoines, Iowa 50311

Dear Kim:

Thank you for your interest in the study, "Knowledge of Medical Terminology Among Hospital Patients." I am enclosing some background information and the questionnaire. You have my permission to use the questionnaire in your study.

I hope this information is useful.

Sincerely,

Jean Byrne, Ph.D.
Associate Professor
Health Education
316 White Hall
(216) 672-7977

JB/cbt
Enclosure
Appendix D

Permission from Institutions
To be completed by the Investigator:

Date Submitted: April 25, 1991

Proposal Title: Knowledge of Health Care Terminology

Investigator: Kimberlee Turner

Faculty research advisor: (for student research): Barbara Haag

Return to: Barbara Haag

Name

Street Address or Campus Office

City, State, Zip if off campus

To be completed by the Human Subjects Research Review Committee Chairperson:

Date Received:

Decision:

- Approval, no risk
- Approval, minimal risk
- Approval, subjects at risk, but benefits outweigh risks
- No approval. Subjects at risk or proposal does not adequately address risks, benefits and procedures.

Reasons for Disapproval:

Suggested Changes:

Human Subjects Review Committee Chair: Hilda L. Williams (1990-1991)

Date: 5/21/91

Final Notification Form
TOPIC: Patient Knowledge/Understanding of Health Care Terminology

DATE COMPLETED: December, 1991

MOTIVATING PROBLEM/METHOD OF IDENTIFICATION: Since cancer is the second highest cause of death in the United States and patients with cancer have extensive contact with the health care system, it is important that these patients understand the terminology being used by their health care professionals.

OBJECTIVES: 1) To assess the knowledge of health care terminology in patients with cancer; 2) To discuss the difference in knowledge of health care terminology when the variables of perceived knowledge level, educational level, marital status, length of time of cancer diagnosis, number of hospitalizations, presence of health care professionals in the family, age, ethnic, origin, sex and urban vs. rural environment are examined. See attached.

PATIENT SAMPLE/METHODS: Sample is limited to those patients diagnosed with cancer from 1984 to present (omitting in situ and benign/borderline cases), at least 18 years old. The Oncology Data Services department will provide mailing labels, omitting deceased patients. In June, 1991, 3,000 - 3,500 IMMC cancer patients will receive two questionnaires in the mail. The first is an Informational Questionnaire which asks questions about the variables described in the Objectives. The second is the Health Care Terminology Questionnaire which includes 50 multiple choice questions regarding terms commonly used by health care professionals. Participants will have two weeks to complete the questionnaires and return them in a self-addressed, stamped envelope.

Oncology Data Services will enter the results into the computer in spreadsheet format for tabulation. For those participants who indicate interest in the tabulated results, a mailing will be completed in January of 1992.
Appendix E

Introductory Letter
Hi, my name is Kimberlee Turner, R.N. I'm a student in the Master of Science in Nursing program at Drake University in Des Moines, Iowa. Conducting a research study is the final requirement for my masters degree and your participation would help me reach my goal.

The research study I have chosen will attempt to determine the level of understanding you, and others like you, have of health care terms which are commonly used by doctors, nurses, and other health care professionals. Determining which health care terms are, or are not, understood will help health care professionals to be more careful when using such terms to explain information which is important to you. This research study is a joint effort with the Cancer Committee at Iowa Methodist Medical Center in Des Moines, Iowa. Therefore, your answers on this questionnaire are very valuable.

There will be approximately 3,500 participants in this research study. Your participation consists of completing two questionnaires. The first is called the Informational Questionnaire and asks questions such as your age and when you were diagnosed with cancer. The second questionnaire, the Health Care Terminology Questionnaire, asks you to answer 50 questions about the meanings of health care terms. Please complete the Health Care Terminology Questionnaire without asking your family or friends for help, or looking up words in the dictionary. The two questionnaires should take about one half hour to complete.

Do not sign your name on either of the questionnaires. Your name will not be used in any tabulations. I am interested only in the combined responses of all who participate in this study.
Your return of the questionnaires indicates your consent to participate in this study. Please return the questionnaires in the enclosed stamped envelope by June 28, 1991. If you are unable to answer the questions, I would appreciate it if you would send a note to me describing the reason for not participating in the study; you may use the addressed stamped envelope for this purpose also.

Participating in this study will not affect your health care in any way. If after beginning you decide to withdraw, you are free to do so without any effect on your health care.

I will send a copy of the correct answers to those who participate. If you would like a copy of the study’s tabulated results, please call Oncology Data Services at Iowa Methodist Medical Center and the results will be mailed when the study is completed. Their phone number is (515) 241-5161; their hours are 8:00 a.m. - 4:30 p.m., Monday through Friday. You may expect to receive these results by January, 1992.

If you have questions or concerns and would like to call me, my phone number is listed below. Or, you may call Oncology Data Services at Iowa Methodist Medical Center at the above phone number.

Thank you for participating in this research study. I hope that it will be as interesting and helpful for you as it has been for me.

Sincerely,

Kimberlee Turner

Kimberlee Turner, R.N.
1547 47th Street
Des Moines, Iowa 50311

Phone: (515) 255-0433 -- Call Collect
Appendix F

Thank You/Reminder Letter
Thank you for participating in the research study on health care terms. If I have not received your questionnaire, I am reminding you how valuable your response is and ask that you complete the questionnaire and return it in the enclosed envelope.

Thank you,

Kimberlee Turner, R.N.
Appendix G

Final Thank You Letter/Correct Answers
JULY 22, 1991

THANK YOU FOR PARTICIPATING IN THE RESEARCH STUDY ON HEALTH CARE TERMS. AS PROMISED I AM ENCLOSING THE QUESTIONNAIRE WITH THE CORRECT ANSWERS HIGHLIGHTED.

SINCERELY,

Kimberlee Turner

KIMBERLEE TURNER, R.N.

enc
HEALTH CARE TERMINOLOGY ANSWER SHEET

The highlighted answer is the correct answer.

1. The abdomen is the part of the body:
   (a) Between the chest and hips
   (b) Between the waist and knees
   (c) Between the head and chest

2. Your doctor tells you that you have a tumor. This means:
   (a) You have a rash
   (b) You have a lump that is cancerous
   (c) You have a lump that may or may not be cancerous

3. Your nurse asks if you have voided. This means:
   (a) Have you urinated?
   (b) Have you vomited?
   (c) Have you passed gas?

4. Cholesterol is found in:
   (a) Foods like eggs, butter and oils
   (b) Vegetables like lettuce and cabbage
   (c) The water we drink

5. The nurse asks if you have constipation. This means:
   (a) You have bloody stools
   (b) You have watery stools
   (c) You have irregular and difficult stools

6. Your doctor says that you have hypertension. This means:
   (a) You have gallbladder problems
   (b) You have high blood pressure
   (c) You have heart problems

7. To say that someone has expired means:
   (a) The person has died
   (b) The person was admitted to the hospital
   (c) Your person was released from the hospital
8. When your pain radiates it means:

(a) Your pain has stopped
(b) Your pain extends from one part of the body to another part
(c) Your pain has gotten worse

9. Every morning the nurse asks if you have had a bowel movement. This means:

(a) Did you turn over in your bed?
(b) Did you have a good night sleep?
(c) Did you pass any stool?

10. Diabetes Mellitus is a disease that causes:

(a) Sugar to be passed in the urine
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11. The doctor tells you that your lungs are congested. This means:

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12. A terminal illness means:

(a) The illness will inevitably cause death
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13. Metastasis refers to:

(a) An examination of the body during an operation
(b) Cancer spreading within the body
(c) A breast being removed
The doctor told a woman that she will have mastectomy. This means:

- To remove a diseased part of the body by an operation
- To transplant a part of the body
- To have an operation

Amputation means:

- Your heart beat stops and starts again
- Your heart beat is fast, hard and irregular
- Your heart beat is very slow

Your doctor asks if you were having palpitations. This means:

- You do not have any feeling in your hands
- You have pain in both hands
- You have swelling of both hands

When you told the doctor that you had numbness in your hands, you meant:

- A specialist doctor
- Another patient who has the same illness as you
- A doctor who works in the hospital while training

The nurse says that the resident will be here to see you. A resident is:

- You take some type of medication at home
- Your body tolerates any medicine
- Your body has a sensitive reaction to the medication

When you tell the nurse that you are allergic to a medication, you are saying:

Where operations are done
Where patients with broken bones are cared for
Where patients with heart problems are cared for

The coronary care unit is the part of the hospital.
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   (a) Your eyes are working
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(c) Go near any radioactive material

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(c) You are to have no visitors
Appendix H

Health Care Terminology Responses
### Health Care Terminology Responses

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