Title

Assessment of knowledge of hypercalcemia in patients at risk to develop cancer-induced hypercalcemia

Author

Coward, Doris Dickerson

Publication Date

1984

Peer reviewed|Thesis/dissertation

ASSESSMENT OF KNOWLEDGE OF HYPERCALCEMIA IN PATIENTS AT RISK TO DEVELOP CANCER-INDUCED HYPERCALCEMIA

by

Doris Dickerson Coward

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

University of California, San Francisco

School of Nursing

ASSESSMENT OF KNOWLEDGE OF HYPERCALCEMIA IN PATIENTS AT RISK TO DEVELOP CANCER-INDUCED HYPERCALCEMIA

ABSTRACT

Cancer patients at risk to develop hypercalcemia (a potentially fatal, but usually reversible complication of malignancy) should be aware of this possible complication, its usual manifestations, the need for prompt medical evaluation, and the measures they can institute to prevent or minimize its occurrence. No documented research was found in which the level of knowledge of hypercalcemia had been determined in this patient population. Orem's model of self-care provided the conceptual framework for this study. Since patients need to know about a health-related deficit before they can participate in self-care, the purpose of this exploratory study was to determine what patients at risk to develop hypercalcemia knew about this possible complication of their malignancy. A four-item Hypercalcemia Knowledge Questionnaire was administered by the researcher in a one-time interview to 40 subjects at risk to develop cancer-induced hypercalcemia. The data were analyzed with descriptive statistics. The findings revealed that neither hospitalized nor outpatient subjects had adequate knowledge of hypercalcemia. Thirty-two (90%) subjects were unaware that hypercalcemia might be a complication of their cancer. Only one subject had knowledge of the symptoms of cancer-induced hypercalcemia.

Twenty-seven (66%) subjects did not recall being told of measures that might prevent the occurrence of hypercalcemia. These findings emphasize the need for health care professionals to educate patients at risk for cancer-induced hypercalcemia so as to enable these patients to participate in self-care.

ACKNOWLEDGMENTS

I would like first to acknowledge and thank the two people who assisted me the most in this accomplishment.

One is my husband, David H. Coward, whose continuing love and encouragement gave me the confidence to begin, to continue, and to complete this research.

The other is my thesis committee chairperson, Marylin J. Dodd, whose love for cancer nursing and for her colleagues was a source of inspiration and much joy as she shared with me her knowledge of the nursing research process.

I would also like to thank the members of my thesis committee, Janet E. DiJulio, Patricia J. Larson, and Connie R. Robinson, for their helpful advice and their several careful critiques of drafts of this thesis. The clarity of the end result is due in no small part to their assistance.

I wish to express my appreciation for the support from my classmates at the University of California, San Francisco, nurses and physicians in the research setting at Stanford University Hospital and, of course, the patients at Stanford University Hospital who served as subjects in my study.

Monetary support from the American Cancer Society, California Division, is also gratefully acknowledged.

TABLE OF CONTENTS

LIST OF TABLES AND FIGURE

CHAPTER I

THE STUDY PROBLEM

Introduction

Patient teaching is an important responsibility of nurses who provide care to people who have cancer. Oncology patients and their family members are often forced by the chronic nature of their disease to participate in the management of their own health care. Knowledge and skills related to that care, which nurses are expected to each, is essential for patient participation.

Hypercalcemia is a fairly common complication of certain types of malignancy in which serum calcium levels in the body rise to greater than 11 mg/100 ml. The condition can be life threatening if not promptly recognized and treated. Because cancer patients and their family members may be in a position to be the first to observe symptoms of hypercalcemia, they need to be taught an awareness of this complication and its possible manifestations.

Statement of the Problem

The level of knowledge of hypercalcemia in cancer patients at risk for hypercalcemia has not been determined.

Purpose of the Study

The purpose of this study is to determine the knowledge level of hypercalcemia in hospitalized cancer patients who are at risk for developing hypercalcemia.

Significance

Cancer-induced hypercalcemia is the most common cause of hypercalcemia in hospitalized patients and is second only to hyperparathyroidism as a cause of hypercalcemia in ambulatory patients (Mundy & Martin, 1982). Although hypercalcemia has been described as a complication of almost every type of cancer, it is most often associated with multiple myeloma, breast cancer with bone metastasis, squamous cell tumors of the lung, head and neck, cervix and ovary, renal cell cancers, and lymphomas (Bull, 1981; Fields, Josse, & Bergsagel, 1982; Trump, 1979). The exact prevalence is unknown, but it is estimated to occur in 20-30% of multiple myeloma patients and in more than 30% of breast cancer patients (Mundy, Ibbotson, D'Souza, Simpson, Jacobs, & Martin, 1984). In a 1974 study by Bender and Hansen, 23% of the patients with squamous cell lung tumors experienced hypercalcemia at the time of diagnosis or during the course of their disease. Stephens, Hansen, and Muggia (1973), in a three-year study of 44 squamous cell head and neck patients, found that 25% had hypercalcemia during the course of their disease. No incidence figures based on research studies could be found for the other cancer sites. The clinical manifestations of hypercalcemia are unpleasant for the patient and may be life threatening (irreversible coma or cardiac arrest) if not quickly recognized and treated. Therefore, symptoms of hypercalcemia in a patient prone to

this disorder should be promptly evaluated by obtaining a serum calcium level.

Patients with chronic illnesses such as cancer must manage their own care between outpatient visits. For those ambulatory cancer patients at risk for hypercalcemia, knowledge about the disorder and its symptoms is obviously a prerequisite for obtaining early diagnosis and treatment. Even during hospitalization, an alert patient or family member may be the first to note symptoms which might be indicative of rising serum calcium levels.

The self-care theoretical model of Dorothea Orem (1980) stresses the role of the nurse in developing in patients and their families the ability to perceive and interpret physical and/or psychological symptoms so as to take appropriate action to avert a crisis. Nurses should be aware of their patients who are prone to hypercalcemia and be knowledgeable about its symptoms. They can then effectively assess their patients' current conditions as well as their learning needs related to hypercalcemia. Nurses also must have knowledge of those teaching strategies that will help educate patients and families about hypercalcemia (Redman, 1981).

The significance of this study, then, is related to three factors. One factor is the predilection to hypercalcemia in patients with certain types of malignancy, the life-threatening aspect of hypercalcemia, and the possibility of its reversal if promptly diagnosed and treated. A second factor is the importance of patients at risk being aware of the disorder and its symptoms so that they can seek essential care promptly. The third factor relates to self-care education by nurses. Nurses are expected to be able to assist patients and family members to gain the

knowledge and skills needed to participate in their own care. This study will focus on determining what hospitalized cancer patients at risk to develop hypercalcemia understand about this potential complication. Once their level of knowledge is determined, future research may focus on enhancing patients' understanding of hypercalcemia.

CHAPTER II

REVIEW OF RELEVANT LITERATURE

In this review, cancer-induced hypercalcemia is discussed from the aspect of its pathophysiology and treatment, incidence, and the nursing literature which suggests nursing interventions in the management of patients prone to cancer-induced hypercalcemia. The concept of self-care will then be discussed from the point of view that self-care is desirable and that patients require specialized knowledge and skills to engage in effective self-care. The section will conclude with a discussion of self-care education that focuses on the need for systematic instruction to enhance patient self-care activities.

Hypercalcemia

The level of calcium in the bloodstream is normally quite stable (9-11 mg/100 ml). It is regulated by calcium absorption from the intestine, calcium excretion by the kidneys, and the constant process of calcium deposition and resorption from the bones. The increased blood calcium levels seen in cancer-induced hypercalcemia are related to excessive calcium resorption which exceeds deposition into bone and the ability of the kidneys to excrete this mineral. Calcium absorption from the intestines does not appear to potentiate the occurrence of

hypercalcemia in cancer patients as calcium absorption has been shown to be low or low-normal when serum calcium levels are elevated in this patient population (Coombs et al., 1976; Stewart et al., 1980).

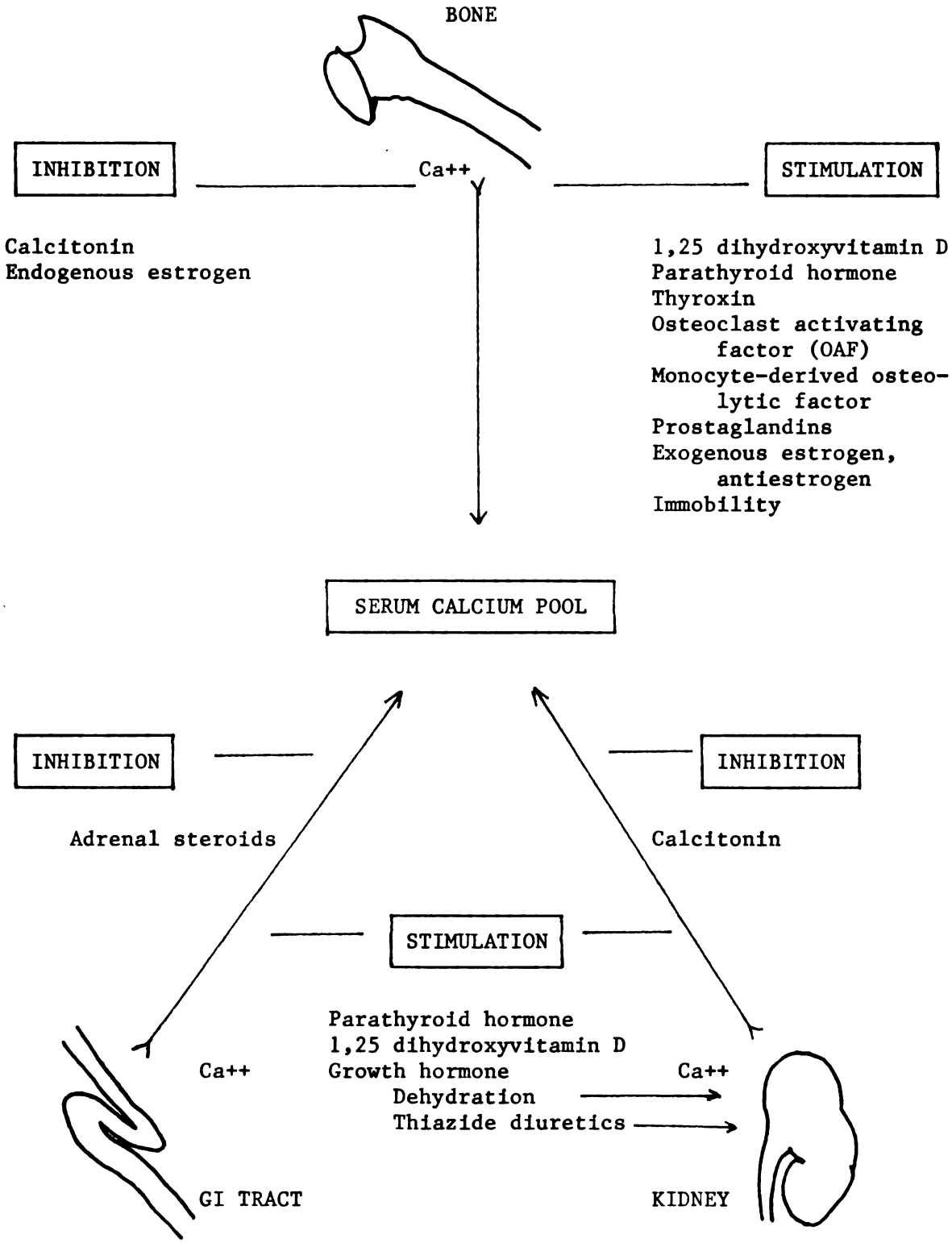
Hypercalcemia in the cancer patient is a potentially lethal, but usually reversible, condition in which a number of factors may be involved. The incidence of hypercalcemia in cancer patients is greater in certain types of malignancy than in others. Seventy percent of all patients with cancer-induced hypercalcemia have metastatic bone cancer (primary site usually the breast or squamous cell carcinoma of the lung), 20% have hematologic malignancies such as myeloma or lymphoma, and 10% have advanced nonmetastatic tumors of the breast, lung, head and neck, cervix, ovary, or kidney (Mundy & Martin, 1982). Metastatic disease in the bone leads to local bone destruction and resorption of calcium. A protein known as osteoclast-activating factor (OAF) is implicated as a cause of increased bone resorption in patients with multiple myeloma and lymphoma. Nonmetastatic tumors may produce metabolic substances that stimulate increased bone resorption. Such substances thus far identified are parathyroid hormone (PTH), PTH-like substances, and prostaglandins of the PGE_2 series. Mundy et al. (1984) have recently hypothesized that a tumor-derived transforming growth factor may also be responsible for bone resorption in some cases.

Hypercalcemia may also be precipitated by estrogen or antiestrogen treatment in patients with disseminated breast cancer (Calabresi & Parks, 1980; Wissing, 1984). The incidence is estimated to be 10% and generally occurs early in the course of hormone therapy. Bull (1981), Mundy and Martin (1981), and Trump (1979) also suggest that the use of

thiazide diuretics may trigger the occurrence of cancer-induced hypercalcemia.

Immobility and dehydration, not uncommon in patients with advanced cancer (or due to an unrelated illness), may also potentiate the development of hypercalcemia. Calcium deposition in bone is enhanced by physical activity, which results in mechanical stress on bones. Prolonged immobilization is associated with an increase in resorption of calcium from the bony skeleton. Dehydration causes a decline in the kidney glomerular filtration rate (GFR). The decline in GFR causes increased reabsorption of sodium in the proximal convoluted tubules in an attempt to promote water conservation. Since sodium and calcium reabsorption are closely linked, calcium is also reabsorbed and can further precipitate the occurrence of hypercalcemia. Factors influencing the development of cancer-induced hypercalcemia and the sites of their action are found in Figure 1.

The symptoms of cancer-induced hypercalcemia are primarily related to the effect of calcium on electrical activity in cell membranes. The excitability of nerve tissue and the contractility of muscle are both dependent on normal circulating levels of calcium. Elevated serum calcium levels depress the excitability of central nervous system neurons and may cause symptoms such as confusion and personality change or drowsiness and lethargy which may lead to stuper, coma, and death if not reversed by treatment. Decreased skeletal muscle cell electrical conduction may lead to feelings of severe fatigue and hypotonia. Depressed cardiac muscle and nerve tissue may permit the occurrence of dangerous cardiac arrhythmias. Increased calcium entry into gastrointestinal smooth muscle cells causes decreased gastrointestinal



Factors Which Affect Serum Calcium Levels and May Influence the Development of Cancer-Induced Hypercalcemia

FIGURE 1

motility and may trigger nausea and vomiting. Elevated serum calcium levels may also lead to impairment of the action of antidiuretic hormone (ADH) on the collecting tubules of the kidney, causing polyuria with an accompanying polydipsia. Table 1 demonstrates the relationships between the effect of increased serum calcium levels on particular body systems and the symptoms of hypercalcemia.

Manifestations of cancer-induced hypercalcemia may occur abruptly or may develop over a period of several days to two weeks. Not all of the symptoms are always present in the face of abnormally high serum calcium levels. In addition, the above-mentioned symptoms are not specific to cancer-induced hypercalcemia. When they are noted, they might be considered to be side effects of medication, due to an unrelated illness, chemotherapy or radiation therapy, or even terminal features of the patient's malignancy. It is important that patients and health care providers be aware that these symptoms <u>may</u> be due to hypercalcemia and should be evaluated by obtaining a serum calcium level.

The primary emergency treatment for hypercalcemia is saline hydration and frequently includes the use of renal loop diuretics (usually furosemide), calcitonin, and glucocorticoids. Once the condition is stabilized, attention is given to preventing its recurrence by correcting the underlying cause (i.e. by excision of the tumor), if possible, or by attempting to inhibit bone resorption with oral administration of phosphates, glucocorticoids (with or without calcitonin), or mithramycin (Mundy & Martin, 1982). Prostaglandin synthesis inhibitors may be given if prostaglandins appear to be the cause of the hypercalcemia. Encouraging the patient to maintain

TABLE 1

Manifestations of Cancer-Induced Hypercalcemia

Body System	Symptoms
Central Nervous System	
Decreased excitability of neurons	Decreased deep tendon reflexes Lethargy ⟨ stupor and coma or restlessness and psychosis
Musculoskeletal System	
Decreased skeletal muscle electrical conduction	Muscle fatigue, weakness, hypotonia
Cardiovascular System	
Decreased contractility	EKG changes
Decreased nerve conduction	Arrhythmias (may lead to cardiac arrest)
Gastrointestinal System	
Decreased smooth muscle contractility	Anorexia, nausea and vomiting, constipation, abdominal pain
Renal	
Interference with ADH	Polyuria ⟶ dehydration, polydypsia
Decreased glomerular filtration rate	Decreased excretion of calcium ⟶ increase in hypercalcemia ⟶ renal failure

adequate hydration and mobilization may also help to prevent recurrence of hypercalcemia (Bergsagel, 1983; Stewart, 1983).

A search of the recent nursing periodical literature revealed several articles on hypercalcemia, the majority of which discussed the subject in relation to malignancy (Cunningham, 1982; Doogan, 1981; Hoffman, 1980; Quinlan, 1982; Rice, 1983; Roberts, 1979; Valentine & Stewart, 1983; Zeluff, 1980). Two of these articles (Cunningham, 1982; Hoffman, 1980) included hypercalcemia in discussions of fluid and electrolyte disturbances and ectopic hormone production associated with malignancy. Cunningham (1982) suggested enlisting help from the patient and family in the treatment of hypercalcemia through the encouragement of increased physical activity and fluid intake. The other three articles (Doogan, 1981; Quinlan, 1982; Valentine & Stewart, 1983) provided thorough discussion of the causes, symptoms, and treatment of cancer-induced hypercalcemia. Both Doogan (1981) and Quinlan (1982) stressed patient and family assistance in diagnosis and treatment and discussed the role of the nurse in patient education.

The emphasis in these articles on patient assistance in the diagnosis and treatment of cancer-induced hypercalcemia leads one to expect that nurses should be involved in the education of patients to become knowledgeable about hypercalcemia. A first step in that education process would be to determine what patients already know about hypercalcemia. No documented research was found in which patient level of knowledge of hypercalcemia had been determined.

Self-care

Chronically ill persons are often forced by the circumstances of their illness to play a major role in their own care. These patients manage their care between hospitalizations (and may assist even during hospitalization) unless they are physically or mentally unable to do so or unless they lack the necessary knowledge and skills. Self-care is defined from the health care consumer's point of view by Levin (1978) as a process by which people can function for their own benefit in health promotion and in disease prevention, detection, and treatment. Self-care is an essential concept in Orem's (1980) model for nursing. She defined self-care as the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being. Both Levin and Orem feel it is important that people assume as much responsibility as they are able for their health care because in doing so they will have more of a sense of control over that part of their life and less dependency on health professionals.

There are many examples of recent nursing research using the self-care model in the chronically ill. Miller (1982) identified 11 categories of self-care needs in ambulatory diabetic patients. One of those categories was the acquiring of knowledge of the disease and the monitoring of self for clues to report to the physician. Hoffart (1982) studied factors that influenced post-renal transplant patients to seek professional care when faced with difficulties in self-care management at home. Recognition of symptoms of potential transplant complications and knowledge of medications were the most frequently reported reasons for seeking care.

In both of the above studies, patient knowledge of their disease and monitoring for symptoms was determined to be a prerequisite for participation in self-care. Several researchers have studied cancer patients' knowledge of their chemotherapy following informed consent procedures which have explained purposes, risks, and benefits of chemotherapy. Both Muss et al. (1979) and Dodd and Mood (1981) found that patients, in spite of having signed informed consent forms, lacked knowledge about their chemotherapy. A second study by Dodd and Mood (1981) determined that cancer patients who received a review of information from a nurse regarding their chemotherapy drugs knew more about their chemotherapy three or four weeks later than did those patients in a control group who did not receive the review. In a subsequent study, Dodd (1982a, 1982b, 1983) assessed self-care behaviors cancer patients used to alleviate side effects of chemotherapy before and after they had received drug information and/or side effect management technique information. She found that patients who had received more side effect management information reported initiating more self-care behaviors. They also initiated self-care behaviors earlier, before side effects became severe. As did the studies with other chronically ill patients, these studies of cancer patients demonstrated that the patients needed a base of knowledge from which to initiate self-care behaviors.

Education for Self-care

Strauss, Fagerhaugh, Suczek, and Weiner (1981) approached the issue of patient education from the perspective of the chronically ill who are already involved in their own care. They felt that patients, from

necessity, perform much of their own health monitoring, even during hospitalizations. These patients should be given credit for the "work" they do and be given careful instruction by nurses so that they can better assist in their care upon their discharge from the hospital. Patients, to effectively perform self-care, need specialized knowledge and skills to manage the new set of health care demands created by their disability and its implications. Levin (1978) considered that the encouragement of self-sufficiency and its positive sequalae is one of the goals of patient education. Orem (1980) stated that educating patients so that they can better participate in their self-care is an appropriate function of nurses and is often a responsibility delegated to nurses.

The teaching of cancer patients by nurses includes encouraging them to participate in self-care. The teaching of adults with cancer was defined by Watson (1982) as the "appropriate method of assisting when the patient is deficient in the skills or knowledge needed to care for himself" (p. 739). She categorized types of learning needs of cancer patients and matched those needs with specific learning activities. In Outcome Standards for Cancer Patient Education, the Oncology Nursing Society Education Committee (1982) stated that nurses should use the teaching-learning process to provide the cancer patient and family with knowledge and skills that will assist them to "maintain, according to ability and desire, a sense of control and participation in one's own health" (p. 7). One of the categories in which nurses are expected to provide knowledge and skills is in the recognition of the manifestations of, and appropriate action for, potential problems of cancer. The learning needs of cancer patients are also identified for nurses in the

Outcome Standards for Cancer Nursing Practice (Oncology Nursing Society & American Nursing Association, 1979) in the statements that the patient and family should "possess knowledge about the disease and therapy in order to attain self-management" (p. 3) and that they should be able to "describe appropriate actions for highly predictable problems, oncologic emergencies, and major side effects of disease or therapy" (p. 4).

Nurses must have the ability to utilize effective teaching strategies to educate the patient and family to participate in self-care related to the potential occurrence of hypercalcemia. Effective education begins with the educator thoroughly understanding the subject to be taught and knowing the learners' needs related to that subject (Redman, 1981). To effectively assist the patient and family to obtain knowledge and skills related to cancer-induced hypercalcemia, nurses themselves must be knowledgeable about this potential complication of malignancy and be able to ascertain their patients' knowledge deficits.

Conceptual Framework

Orem's (1980) self-care model for nursing is the conceptual basis of this study. Her view is that the special concern of nursing is to assist patients to engage in self-care and that individuals benefit from nursing only if they cannot meet their self-care requisites without assistance. She identified three requisites of self-care. (1) Universal self-care requisites focus on life processes and the maintenance of human structure and function. (2) Developmental self-care requisites are associated with human development and the conditions or events that adversely affect it. (3) Health deviation

self-care requisites arise from illness or injury and from medical diagnosis and treatment of pathologic conditions.

At the root of Orem's philosophy is the belief that man has the innate ability to care for himself. Because knowledge, and the skills to apply that knowledge, are necessary for self-management, the self-care model bases self-care behaviors on knowledge. Individuals with health deviation self-care requisites are in need of specialized knowledge in order to meet their self-care demands. Orem believes that nurses are in a position to provide the specific information those individuals need to prevent complications, to live with their disabilities, and to maintain a sense of control over that part of their lives.

Knowledge of complications may be life saving to certain patients, one category of which is the chronically ill ambulatory patient who must manage much of her/his care without direct health supervision. Cancer-induced hypercalcemia is an example of a complication that may quickly become life threatening. It is appropriate, using Orem's model, that patients prone to hypercalcemia and their family members be taught by nurses to recognize its symptoms and to seek prompt evaluation of those symptoms by a health care provider. An essential first step toward planning nursing interventions to enhance patients' knowledge and skills related to this possible complication of their cancer is to assess their current level of knowledge of cancer-induced hypercalcemia.

CHAPTER III

METHODOLOGY

The specific aim of this study was to determine what cancer patients at risk for developing cancer-induced hypercalcemia knew about this possible complication of their malignancy.

Research Method and Design

The literature survey failed to reveal previous research in the area of patient knowledge of cancer-induced hypercalcemia. Therefore, an exploratory study was the research method of choice. A structured questionnaire designed to measure the level of patient knowledge of hypercalcemia was administered by the researcher during a one-time interview. The questionnaire included demographic items. It was anticipated that selected demographic variables might be related to the subject's level of knowledge.

A threat to the internal validity of this nonexperimental study was the lack of control over extraneous variables. History, maturation, testing, and mortality were not threats in this one-time structured interview. The threat of instrumentation was controlled for by the use of a standardized questionnaire which was administered in the same manner by the same interviewer with each subject. Researcher bias,

although present, should not have adversely influenced the study as the variable of knowledge was more concrete and nonthreatening when compared to other research areas (e.g. attitudes, values, and beliefs).

It was expected that although the findings of this study would be related to hospitalized patients, they would also be applicable to ambulatory cancer patients at risk to develop cancer-induced hypercalcemia. During the course of a chronic illness such as cancer, a patient may expect to experience several hospitalizations interspersed with periods of ambulatory outpatient care. Hospitalized patients with diagnoses which placed them at risk to develop hypercalcemia were chosen for this study for the convenience of the researcher.

Because this was an exploratory study, there were no identified independent or dependent variables. The assumptions made of this study were that the patients would accurately recall that they had or had not been told (a) the they were at risk to develop hypercalcemia, (b) the manifestations of hypercalcemia, and (c) the measures they might take to prevent hypercalcemia.

Definition of Terms

Hypercalcemia - A potentially fatal, but usually reversible, condition characterized by variable multisystem manifestations and verified by a serum calcium level greater than 11 mg/100 ml.

Cancer-induced hypercalcemia - Increased serum calcium level due to bone destruction caused by (a) direct invasion of bone by a metastatic tumor or (b) stimulation of bone resorption by parathyroid hormone (PTH) or a PTH-like substance secreted by a tumor.

Patient at risk to develop hypercalcemia - Hospitalized patient with an admission diagnosis of breast cancer with skeletal metastases, multiple myeloma, lymphoma, renal cell cancer, or advanced squamous cell cancer of the lung, head and neck, cervix, or ovary.

Knowledge of hypercalcemia - The recognition of hypercalcemia as a potential complication of cancer, the ability to identify its symptoms, and knowledge of possible means of prevention as measured by the Hypercalcemia Knowledge Questionnaire (HKQ).

Description of the Research Setting

The setting for the study was Stanford University Hospital, a 660-bed acute care, teaching, and research center. The data collection took place in the patients' rooms on the cancer research, medical, and surgical units and in two outpatient clinics. (The inclusion of outpatient subjects will be discussed in Chapter IV.) The interviews were conducted during the months of June through September 1984.

Sample

The subjects were outpatient and hospitalized patients over the age of 18 with diagnoses of metastatic bone cancer, multiple myeloma, renal cell cancer, and advanced squamous cell cancer of the lung, head and neck, and kidney. Names and diagnoses were obtained from a daily computer printout of the hospital census. Additional selection criteria were (a) the ability to understand English and (b) the physical and mental competence to participate in the study.

The sample size was to be at least 30. The final sample size was to depend on the content of the initial data and the number of available

subjects during the proposed time period. A total of 43 subjects were interviewed, of which 40 were included in the final study.

Human subjects' assurance from the patients' perspective included a verbal and written explanation of the study (Appendix A) by the researcher. A consent form for research subjects for the University of California, San Francisco (Appendix B) was developed but not used. An informed consent form was signed by each subject for Stanford University Hospital (SUH) (Appendix C). Consent was previously obtained from the Protection of Human Subjects Committees at SUH and the University of California, San Francisco (UCSF).

Instrument

The instrument used in this study was the Hypercalcemia Knowledge Questionnaire (HKQ) (Appendix D) developed by the researcher. The conceptual basis of the HKQ was the Chemotherapy Knowledge Questionnaire used by Dodd (1982b) to measure cancer patients' knowledge of chemotherapy. The reliability of Dodd's instrument was established by its use in two previous studies by Dodd and Mood (1981). Since the HKQ was newly developed for this one-time interview, the reliability of this instrument has not been established.

The content validity of the HKQ was established by information found in the literature on cancer-induced hypercalcemia. Content validity was further established by consultation with experts who provide care to cancer patients. The face validity was established by using the questionnaire in a pilot study of five patients.

The HKQ instrument consisted of two parts. Part One contained 14 demographic items which were completed by the researcher with the

assistance of the research subject and by consulting his/her medical record. Part Two contained four knowledge of hypercalcemia items with dichotomous "yes" and "no" response format and fill-in of short answers. The researcher and the subject read the items together and the investigator recorded the patients' responses. Part Two was scored by counting each "yes" answer as one point. The highest possible score of 13 points indicated a high level of knowledge of hypercalcemia, its manifestations, and measures to take to minimize its occurrence. The fill-in short-answer questions were tabulated separately.

Procedure

Potential subjects were identified from the hospital census. A potential subject's chart was reviewed to determine if his/her diagnosis and condition fit the criteria for a subject in this study. Permission to interview a potential subject was obtained from his/her physician. A potential subject's current physical and mental competence to be interviewed was ascertained from discussion with his/her nurse prior to approaching the subject. At a time convenient to the subject, a meeting was arranged with the researcher. The subject was given the verbal and written explanation of the study. The subject was guaranteed the confidentiality and anonymity of his/her response by the assignment of a code number instead of using his/her name. The subject's consent was obtained and the HKQ was administered.

The HKQ was administered in the same manner and by the same researcher for each subject. The HKQ was administered only under circumstances where the subject was comfortable and not distracted by other procedures, visitors, TV, etc. After the HKQ was completed, the

subject was given the opportunity to ask questions about cancer- induced hypercalcemia. Most subjects asked for and were given verbal information about hypercalcemia, its usual symptoms, and measures to institute to possibly prevent its occurrence. The fact that restriction of dietary calcium was not necessary was also discussed with most patients.

CHAPTER IV

RESULTS

The Pilot Study

Consents to conduct the study were obtained from the Human and Environmental Protection Committee at University of California, San Francisco (UCSF) in May 1984 and from the Committee for the Protection of Human Subjects in Research at Stanford University Hospital (SUH) in early June. UCSF did not require that the subjects sign an informed consent form for their institution because the study was to be conducted at SUH. Therefore only one informed consent form was signed by each subject (Appendix C).

The pilot study of five patients resulted in several methodological modifications. A major change was in the classifications of patients to be included in the study. Although the literature reviewed by the researcher stated that lymphoma patients were prone to hypercalcemia, physicians and nurses at SUH indicated that they rarely saw hypercalcemia in these patients. A further search of the literature revealed that hypercalcemia is most often seen in patients with Burkitt's lymphoma and in adult T-cell lymphomas associated with the human T-cell leukemia/lymphoma virus #1 (HTLV) (Blayney et al., 1983; Grossman et al., 1981; Mundy et al., 1984). Adult patients with the

diagnoses of Burkitt's lymphoma or HTLV #1 associated adult T-cell lymphoma are rarely seen in the population of lymphoma patients at SUH. It would not be reasonable to expect patients whose types of lymphoma were not those which put them at considerable risk to develop hypercalcemia to have been told of this condition by health care professionals. Therefore, the two lymphoma patients from the pilot study were eliminated and no further lymphoma patients were used as subjects.

A similar situation occurred when the researcher discussed cancer-induced hypercalcemia with physicians and nurses caring for patients with gynecological cancers. The reviewed literature had suggested that patients with squamous cell cancer of the cervix and ovary were prone to hypercalcemia. A further search revealed that those statements were based on 32 case histories (Holtz, 1980; Stewart et al., 1982). No incidence rates for hypercalcemia in patients with squamous cell cancer of the cervix or ovary could be found in the literature. Holtz (1980) felt that hypercalcemia might be reported more frequently in these patients if health care professionals were more aware of the possibility of its occurrence in this group. However, as in the lymphoma patients, it was not reasonable to expect that patients with squamous cell cancer of the cervix and ovary would have been told of hypercalcemia by health care professionals. Therefore, patients who had this type of cancer were not included in the study.

Another type of cancer which is associated with hypercalcemia was added to the study at this time. Sclerosing cholangiocarcinoma had not been included because it is a very rarely occurring cancer (Mundy et al., 1984; Peters, 1976). Two such patients were admitted to SUH during

the study, one of whose initial signs and symptoms were due to hypercalcemia.

One subject was eliminated from the pilot study because he insisted that his wife answer the questions for him. This was not meant to indicate that family members should not have knowledge of cancer-induced hypercalcemia. Indeed, they are are more frequently in a position to note early symptoms of this condition than are health care providers. An alert family member might also recognize symptoms of the problem more readily than the patient experiencing them. However, the study was designed to assess knowledge of patients, not family members. The inclusion of the responses of family members would have been variable among subjects and may have resulted in subjects with family members present during the interview scoring higher on the Hypercalcemia Knowledge Questionnaire (HKQ) than subjects who had no family members present. Therefore, this subject was eliminated from the study, and family members of subsequent subjects were not permitted to answer questions for the subject.

It was also decided at this time to include ambulatory patients from the two types of cancer most likely to be associated with cancer-induced hypercalcemia: multiple myeloma and breast cancer with skeletal metastasis. Permission was obtained to interview patients from the Stanford Oncology Service Daycare Center and the Stanford Hematology Clinic, both of which are part of the SUH Medical Service.

Finally, as a result of the pilot study, one item was changed on the HKQ, Part II. When assessing patient knowledge of central nervous system symptoms of hypercalcemia, it was deemed more appropriate to ask

if subjects had been told to report signs of "mental confusion" rather than "personality change" as it was asked in the original questionnaire.

Demographics of the Sample

Table 2 presents the demographic characteristics of the 40 subjects in the sample. The age range of the subjects was 31-78 years with a mean of 59.6 years (SD = 12.4). A majority of the subjects were female (n = 24). The subjects were predominantly Caucasian. Twenty-four of the subjects had at least some college education. There was a dispersion in occupations (or former occupations) between major professionals and semi-skilled workers.

The distribution of the inpatient subjects in the various cancer diagnosis categories reflects the hospital admission census during the time period of the study. After potential subjects were identified from the admission census, their charts were reviewed to determine how prone each one was to hypercalcemia. For instance, a patient whose diagnosis was breast cancer but who was hospitalized for the first time for tumor excision would not be considered prone to hypercalcemia. Also, newly diagnosed cancer patients were not interviewed because it was anticipated that health care professionals might not yet have discussed cancer-induced hypercalcemia with them. (The two subjects who were interviewed within the first two months after diagnosis of cancer had presented with hypercalcemia and were therefore expected to have knowledge of the condition.)

The outpatient subjects were interviewed during their clinic visits. The breast cancer patients (n = 7) were seen in the Oncology Daycare Center and the multiple myeloma patients (n = 7) at the

TABLE 2

Demographic Characteristics of the Subjects

Characteristic	n	Characteristic	n
Sex		**Race**	
Female	24	Caucasian	38
Male	16	Asian	2
Education		**Occupation**	
Graduate professional	7	Exec., major professional	4
College graduate	4	Manager, lesser prof.	7
Partial college	13	Minor prof., adm. personnel	7
High school graduate	10	Clerical, technician	10
Partial high school	3	Skilled worker	7
Junior high school	2	Semiskilled worker	5
> 7 yrs. education	1		
Inpatient Cancer Diagnosis		**Outpatient Cancer Diagnosis**	
Breast cancer	11	Breast cancer	7
Multiple myeloma	1	Multiple myeloma	7
Renal cell	2	Renal cell	3
Squamous cell lung	4	Squamous cell lung	1
Squamous cell head & neck	3		
Cholangiocarcinoma	1		
total	22	total	18
Health Supervision		**Subject Performance Status (AJCC)***	
Private physician	9	0 = Normal activity	5
Medical school teaching service	22	1 = Symptoms but ambulatory	22
Private MD and teaching service	6	2 = In bed < 50% of time	5
Other health plan and teaching service	3	3 = In bed ⩾ 50% of time	4
		4 = Bedridden (100%)	4
		* American Joint Committee on Cancer (1983)	

Hematology Clinic. The renal cell cancer subjects (n = 3) and the squamous cell lung cancer subject were ambulatory participants in a Phase I Beta-interferon study at SUH.

All of the breast cancer subjects (n = 18) had skeletal metastasis. The subjects with diagnoses of squamous cell cancer of the lung (n = 5), head and neck (n = 3), or renal cell cancer (n = 5) either had advanced disease and nonresectable tumors or were receiving palliative treatment for recurrent disease. In addition to being prone to hypercalcemia because of their type of cancer, 17 of the subjects had received, or were currently receiving, medications known to predispose patients to this condition. Twelve breast cancer subjects were taking, or had taken in the past, the antiestrogen tamoxifen citrate. Five subjects were taking, or had taken, thiazide diuretics; two subjects were taking both medications at the time of the interview.

The majority of the subjects (n = 22) were receiving health care from the medical school teaching service. A few subjects were under the care of private physicians (n = 9); some received care from both private physicians and the teaching service (n = 6), and three had been sent from another health plan's clinic to SUH for further evaluation or treatment.

Most of the subjects in this study had symptoms of their disease, but were able to perform a major portion of their own care. Their physical performance was assessed by using the American Joint Committee on Cancer (AJCC) Host Performance Scale. This scale was developed by the AJCC (1983) and is a simplification of the frequently used Karnofsky and Eastern Cooperative Oncology Group (ECOG) scales. Table 3 expands on the patient physical performance scores and compares performance scores and cancer diagnoses.

TABLE 3

Subject Performance Scores by Cancer Diagnosis

AJCC* Scores	Breast (n)	MM (n)	Lung (n)	H & N (n)	Renal (n)	Chol (n)	Total
0	1	3	1	0	0	0	5
1	11	4	2	1	3	1	22
2	2	1	0	2	0	0	5
3	3	0	0	0	1	0	4
4	1	0	2	0	1	0	4
Total	18	8	5	3	5	1	40

MM = multiple myeloma; H & N = head & neck; Chol = cholangiocarcinoma

Average Subject Performance Scores by Cancer Diagnosis

Total Subjects	1.5
Multiple myeloma	.8
Cholangiocarcinoma	1.0
Squamous cell lung	1.6
Breast	1.6
Squamous cell head & neck	1.7
Renal cell	2.0

* American Joint Committee on Cancer (1983) performance status as determined by patient in performing activities of daily living. (0 = Normal activity; 1 = Symptomatic and ambulatory, cares for self; 2 = Ambulatory more than 50% of time, occasionally needs assistance; 3 = Ambulatory 50% or less of time, nursing care needed; 4 = Bedridden, may need hospitalization)

The length of time in months since diagnosis was determined for each type of cancer and is presented in Table 4. The breast cancer subjects had been ill the longest, the lung cancer subjects the shortest length of time. This reflects the usual survival rates for these types of cancer.

TABLE 4

Length of Time Since Cancer Diagnosis

		Time Since Diagnosis (in months)		
Cancer Diagnosis	n	Range	Mean	SD
Total subjects	40	1 - 264	50.9	58.7
Breast cancer	18	9 - 264	69.6	67.5
Multiple myeloma	8	5 - 165	59.0	53.3
Squamous cell head & neck	3	2 - 101	38.0	44.3
Renal cell	5	2 - 93	25.0	34.5
Squamous cell lung	5	1 - 21	12.2	9.3
Cholangiocarcinoma	1	2		

Questionnaire Results

The knowledge of these subjects of cancer-induced hypercalcemia, its manifestations, and measures they might take to possibly minimize its occurrence was poor. The range of scores on the HKQ was 0 to 10 (out of a possible score of 13) with a mean of 1.8 (SD = 2.6).

Awareness of hypercalcemia. Thirty-two of the 40 subjects (90%) stated that they had not been aware of the word "hypercalcemia" before the researcher mentioned it to them in the explanation of the study. Of the eight subjects who answered that they had a previous awareness of the word "hypercalcemia", three had the condition currently and two had experienced it earlier in the course of their cancer. Thirty-five of the 40 subjects (88%) could not recall being told that hypercalcemia might be a complication of their cancer. Three of the five who remembered being told recalled that they had been told by their physician. A fourth subject had read about it in a medical journal while in a public library looking for information about his newly diagnosed multiple myeloma. The fifth subject who knew that hypercalcemia might be a complication of her breast cancer was a registered nurse whose husband was a physician.

Knowledge of symptoms of hypercalcemia. It was thought that patients who were prone to hypercalcemia might have forgotten "hypercalcemia", but would remember being told to report symptoms of the condition. Therefore, they were read the list of possible symptoms of cancer-induced hypercalcemia and asked if they recalled being told to report the occurrence of those symptoms to a health care provider. Eight of the 40 subjects (20%) recalled being told about the possibility of the occurrence of nausea and vomiting, but four of these felt it was in relation to chemotherapy, not hypercalcemia.

Six of the 40 subjects (15%) recalled either being told to report extreme fatigue and muscle weakness or being asked during a clinic visit if these symptoms had occurred since their last appointment. Thirty-seven of the subjects (93%) did not recall being asked to report

an unexplained increase in thirst or an increase in frequency of urination. Of the three who knew to report these symptoms, two were multiple myeloma patients who said they were routinely asked during clinic visits if they had experienced increased thirst or increased frequency of urination since the last visit. The third subject who knew to report these symptoms was the previously mentioned multiple myeloma patient who, on his own, went to the library to research his disease entity. Two subjects knew to report the symptom of mental confusion. One was a squamous cell lung cancer patient who was hypoxemic due to pulmonary emboli; the other was the previously discussed multiple myeloma patient.

Only one subject was aware that the symptoms of hypercalcemia might occur suddenly or might develop over a few days or a week or two. This was a breast cancer patient who had experienced hypercalcemia three times in the previous five months. If subjects recalled that they had been told the symptoms of hypercalcemia, they were then asked what they had been told to do if the symptoms occurred. Four subjects recalled that they were told to call their physician. One recalled being told to report to his physician any unusual, persistent problem.

Prevention of symptoms of hypercalcemia. The literature on cancer-induced hypercalcemia suggested that its symptoms might be minimized by drinking adequate amounts of liquids and by being as mobile as possible. It was expected that patients who were at risk to develop cancer-induced hypercalcemia would have been told to do these things by a health care professional. Twenty-seven of the 40 subjects (68%) could not recall being told to do either of these things. Ten of the 13 who recalled being told stated that it was the physician who told them. One

subject recalled being told to perform these measures by a medical student, one by both her physician and a nurse, and one by a nurse. When these 13 subjects were asked if they had been told why attention to these measures was necessary, five answered "yes". An example of what they recalled being told as the reason for drinking an adequate amount of liquid and staying mobile was typified by the response of a multiple myeloma patient: "I was told to walk because of my disease and to drink because of the prednisone I was taking" (i.e. the rationale was incorrect).

Knowledge of serum calcium levels. A final question was asked to further ascertain the subjects' levels of understanding about hypercalcemia. They were asked if their blood calcium level was checked when their blood was drawn for routine laboratory tests. Thirty-three (83%) subjects stated that they did not know if calcium in their blood was determined when blood tests were performed; five subjects answered "yes"; two were sure that it was not checked.

As was stated previously, three subjects had hypercalcemia at the time of the interview and two others had experienced it earlier during the course of their cancer. These five subjects might have been expected to be more knowledgeable about hypercalcemia than subjects who had not experienced this complication. Such was not the finding in this study. The five subjects knew that hypercalcemia meant that there was too much calcium in their blood and that it was related to their cancer. No one knew that the increased serum calcium was from increased bone resorption. The breast cancer patient who had experienced hypercalcemia three times in the past five months had been told to restrict her intake

of calcium-containing foods. She, therefore, thought that her hypercalcemia was caused by dietary intake of calcium.

None of these five subjects had known previous to the experience with hypercalcemia that the condition might be a complication of their cancer. They did not recall, even after having had hypercalcemia, being told what manifestations they might have if they again experienced this condition. They were able to recall the symptoms they themselves had experienced. Only two of these five subjects recalled being told by health professionals that it was important for them to stay as mobile as possible and to drink an adequate amount of liquid. All of these subjects did state that, when their blood was drawn for laboratory tests, calcium levels were checked.

In summary, the results of the Hypercalcemia Knowledge Questionnaire indicated that, in total, patients lacked knowledge about hypercalcemia, its manifestations, and measures they might perform to minimize those manifestations. It had been anticipated that the demographic data could be related to the subject's level of knowledge and that correlational analysis would be performed between selected demographic variables and scores on the HKQ. However, due to the subjects' very low knowledge scores and the lack of dispersion of demographic data, correlational analysis was prohibited.

CHAPTER V

DISCUSSION

Conceptual support for patients and family member caregivers taking as much responsibility as they are able for their health care is found in the self-care movement (Levin, 1978) and is inherent in Orem's (1980) self-care model for nursing. It is also emphasized specifically for cancer patients in the Outcome Standards for Cancer Nursing Practice (Oncology Nursing Society & American Nursing Association, 1979) and the Outcome Standards for Cancer Patient Education (Oncology Nursing Society Education Committee, 1982). Both of the Outcome Standards and Orem confirm the belief that nurses have the responsibility to educate patient and their family members to engage in self-care. In both sources, the assumption is made that nurses have the ability to teach the specialized knowledge and skills that patients and family members require to best manage their own care.

The body of knowledge patients need to have to assist in the management of their own care related to hypercalcemia is established in the medical and nursing cancer-induced hypercalcemia literature (Bergsagel, 1983; Cunningham, 1980; Doogan, 1981; Hoffman, 1980; Quinlin, 1982; Stewart, 1983). It is therefore reasonable to expect that patients at risk to develop cancer-induced hypercalcemia would have

been taught by health care professionals about the condition, its usual manifestations, and the means to prevent or minimize its occurrence. The results of this exploratory study of 40 ambulatory and hospitalized patients indicated that they, in general, were poorly informed. These findings are consistent with the lack of cancer patients' knowledge of their chemotherapy in three previous studies (Dodd, 1982a, 1982b; Dodd & Mood, 1981; Muss et al., 1979).

There are several possible reasons why the subjects in this present study performed so poorly on the Hypercalcemia Knowledge Questionnaire (HKQ). First, it is possible that they had not been previously informed about hypercalcemia as a potential complication of their cancer. Second, they may have been told previously, but could not recall their knowledge because of failure in the teaching-learning process. Third, they may have been told previously, but could not recall due to circumstances of their current condition, distractions in their physical environment, or the threat of the research situation. Fourth, it is possible that the HKQ did not measure the subjects' actual knowledge of hypercalcemia.

The third and fourth possible reasons are thought not to have affected the findings of this study. The researcher included only subjects whose physical and mental condition permitted interviewing, arranged interviews in periods of minimal environmental distraction, and presented the study as nonthreatening exploratory research. The HKQ itself is a short, easily administered tool which comprehensively covers several aspects of knowledge concerning a concrete topic. Its content validity was established from the cancer-induced hypercalcemia literature and from discussion with experts in the field of oncology.

It, therefore, is presumed to be a valid measure of hypercalcemia knowledge.

It is probable, then that the subjects in this study either had not been told about cancer-induced hypercalcemia or had been told in such a manner that they could not later recall what they should know about this condition. Generalizations cannot be made from the findings in a small convenience sample to the larger population of patients at risk to develop cancer-induced hypercalcemia. With the recognition of the limitations of this study in mind, implications for nursing education, practice, and research based on the findings will be discussed.

Implications for nursing education include both assuring nurses' knowledge about cancer-induced hypercalcemia and teaching nurses how to provide self-care education related to hypercalcemia to patients. Lack of knowledge of hypercalcemia in the subjects in this study may have resulted from knowledge deficits in the nurses who provided their care. The nurses' knowledge was beyond the scope of this study. However, casual conversation with staff nurses involved in the care of cancer patients suggested to the researcher that those nurses needed more knowledge themselves to adequately assess their patients who were at risk to develop cancer-induced hypercalcemia.

Because oncologic emergencies, such as hypercalcemia, may not be taught in fundamental nursing education classes, continuing education nursing educators should include oncologic emergencies in courses provided for nurses working with oncology patients. Hospitalized subjects in this particular study were admitted not only to oncology units, they were also found on general surgical and orthopedic units. Inservice educators should plan strategies to help nurses on these

"non-oncology" units be aware of hypercalcemia as a potential complication of their patients' cancers.

Both fundamental nursing education and continuing education programs should emphasize the importance of teaching patients to engage in self-care. Patients such as the subjects in this study who were chronically ill (the mean length of time since diagnosis of cancer was 50.9 months) must manage much of their own care while not under direct supervision of health care professionals. Nursing education which provides strategies for educating patients in self-care has obvious value for these patients and their families.

Implications for nursing practice involve assessment of cancer patients for manifestations of hypercalcemia and the education of patients in self-care related to cancer-induced hypercalcemia. Nurses caring for patients who are experiencing hypercalcemia, or who are at risk to develop hypercalcemia, have a responsibility to understand the condition, to recognize manifestations of hypercalcemia, and to be knowledgeable about methods of treatment. Nurses also have responsibility to teach patients and family member caregivers skills related to maintaining mobility and adequate hydration in order to minimize the occurrence of symptoms of hypercalcemia. Patients also need to be taught awareness of the condition and its manifestations so that they can seek prompt evaluation of symptoms by a health care professional.

There is an additional implication for nursing practice in the encouragement of patient and family member awareness of cancer-induced hypercalcemia. Inherent in the self-care model is the belief that patients have the right to participate in the decisions being made

concerning the management of their illness and the circumstances surrounding the quality of the life they will live. Cancer-induced hypercalcemia may be the initial symptom of a malignancy, but it often occurs during the terminal stage of disease. In patients with disseminated and no longer treatable disease, the development of hypercalcemia may provide the opportunity for choosing to prolong life or to avoid prolonged dependence and suffering. Patients and family members who have an awareness of cancer-induced hypercalcemia are in a position to assist their health care providers to make these kinds of decisions.

Nursing research using the HKQ in a different patient setting and with a larger or more homogeneous group (using only one or two types of cancer) of subjects would expand on the findings of this study of knowledge of hypercalcemia in patients at risk to develop cancer-induced hypercalcemia. Research could also be done to better document the incidence of hypercalcemia in particular cancers with the aim of identifying those patients at most risk and therefore in most need of education about this complication. There is also a need for patient education materials to be developed and researched as to their effectiveness in enhancing knowledge of hypercalcemia in patients at risk to develop cancer-induced hypercalcemia.

REFERENCES

American Joint Committee on Cancer. (1983). Manual for staging cancer (2nd ed.). Philadelphia: Lippincott.

Bender, R.A. & Hansen, H. (1974). Hypercalcemia in bronchogenic carcinoma. Annals of International Medicine, 80, 205-208.

Bergsagel, D.E. (1983). Plasma cell myeloma. In W.J. Williams, E. Buetler, A.J. Erslev, & M.A. Lichtman (Eds.), Hematology. New York: McGraw-Hill.

Blayney, D.W., Jaffe, E.S., Fisher, R.I., Schechter, G.P., Cossman, J., & Robert-Guroff, M. (1983). Human T-cell leukemia/lymphoma virus, lymphoma, lytic bone lesions, and hypercalcemia. Annals of Internal Medicine, 98, 144-151.

Bull, F. (1981). Hypercalcemia in cancer. In J. Yarbo & R. Bornstein (Eds.), Oncologic emergencies. New York: Grune & Stratton.

Calabresi, P. & Parks, R. (1980). Antiproliferative agents and drugs used for immune suppression. In A. Gilman, L. Goodman, & A. Gilman (Eds.), The pharmacological basis of therapeutics (pp. 1301-1305). New York: Macmillan.

Coombes, R.C., Ward, M.K., Greenberg, P.B., Hillyard, C.J., Tulloch, M.S., Morrison, R., & Joplin, G.F. (1976). Calcium metabolism in cancer: Studies using calcium isotopes and immunoassays for parathyroid hormone and calcitonin. Cancer, 38, 2100-2120.

Cunningham, S.G. (1982). Fluid and electrolyte disturbances associated with cancer. Nursing Clinics of North America, 4, 579-593.

Dodd, M.J. (1982a). Assessing patient self-care for side effects of cancer chemotherapy - Part 1. Cancer Nursing, 5, 447-451.

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

Dodd, M.J. (1983). Self-care for side effects in cancer chemotherapy: An assessment of nursing interventions - Part 2. Cancer Nursing, 6, 63-67.

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

Doogan, R.A. (1981). Hypercalcemia of malignancy. Cancer Nursing, 4, 299-304.

Fields, A.L.A., Josse, R.G., & Bergsagel, D.F. (1982). Metabolic emergencies. In V. De Vita, S. Hellman, & S. Rosenberg (Eds.), Cancer: Principles and practice of oncology. Philadelphia: Lippincott.

Grossman, B., Schechter, G.P., Horton, J.E., Pierce, L., Jaffe, E., & Wahl, L. (1981). Hypercalcemia associated with T-cell lymphoma/leukemia. American Journal of Clinical Pathology, 75, 149-155.

Hoffart, N. (1982). Self-care decision making by renal transplant patients. American Association of Nephrology Nurses and Technicians, 6, 43-47.

Hoffman, J.T. (1980). Syndromes of ectopic hormone production in cancer. Nursing Clinics of North America, 3, 499-510.

Holtz, G. (1980). Paraneoplastic hypercalcemia in gynecologic malignancy. Obstetrical and Gynecological Survey, 35, 129-135.

Levin, L.S. (1978). Patient education and self-care. Nursing Outlook, 3, 170-175.

Mundy, G.R., Ibbotson, K.J., D'Sousa, S.M., Simpson, E.L., Jacobs, J.W., & Martin, T.J. (1984, June 28). The hypercalcemia of cancer: Clinical implications and pathogenic mechanisms. New England Journal of Medicine, 1718-1727.

Mundy, G.R. & Martin, T.J. (1982). The hypercalcemia of malignancy: Pathogenesis and management. Metabolism, 12, 1247-1276.

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

Oncology Nursing Society & American Nursing Association, Division on Medical-Surgical Nursing Practice. (1979). Outcome standards for cancer nursing practice. Kansas City, MO: American Nurses Association.

Oncology Nursing Society Education Committee. (1982). Outcome standards for cancer patient education. Pittsburgh, PA: Oncology Nursing Society.

Orem, D.E. (1980). Nursing: Concepts of practice. New York: McGraw-Hill.

Quinlin, M. (1982). Solving the mysteries of calcium imbalance: An action guide. RN, 11, 50-54, 100.

Peters, R.L. (1976). Pathology of hepatocellular carcinoma. In K. Okuda & R. Peters (Eds.), Hepatocellular carcinoma. New York: Wiley.

Redman, B.K. (1981). Issues and concepts in patient education. New York: Appleton-Century-Crofts.

Rice, V. (1983). Magnesium, calcium, and phosphate imbalances: Their clinical significance . . . home study program. Critical Care Nurse, 3, 90-112.

Roberts, A. (1979, June 9). Systems of life: Calcium homeostasis regulation. Nursing Times.

Stephens, R.L., Hansen, H.H., & Muggia, F.M. (1973). Hypercalcemia in epidermoid tumors of the head and neck and esophagus. Cancer, 31, 1487-1491.

Stewart, A.F. (1983). Therapy of malignancy-associated hypercalcemia: 1983. American Journal of Medicine, 74, 475-480.

Stewart, A.F., Horst, R., Deftos, L.J., Cadman, E.C., Lang, R., & Broadus, A.E. (1980, December 11). Biochemical evaluation of patients with cancer-associated hypercalcemia. New England Journal of Medicine, 303, 1377-1383.

Stewart, A.F., Romero, R., Schwartz, R.E., Kohorn, E.I., & Broadus, A.E. (1982). Hypercalcemia associated with gynecological malignancies: Biochemical characterization. Cancer, 49, 2389-2394.

Strauss, A.L., Fagerhaugh, S., Suczek, B., & Weiner, C. (1981). Patients' work in the technologized hospital. Nursing Outlook, 7, 404-412.

Trump, D.L. (1979). Abnormalities of bone and mineral metabolism. In M. Abeloff (Ed.), Complications of cancer: Diagnosis and management. Baltimore: Johns Hopkins University Press.

Valentine, A.S. & Stewart, J.S. (1983). Oncogenic emergencies. American Journal of Nursing, 83 (9), 1282-1285.

Watson, P. (1982). Patient education: The adult with cancer. Nursing Clinics of North America, 4, 739-752.

Wissing, V.S. (1984). The hormone factor. American Journal of Nursing, 84, 1117-1118.

Zeluff, G.W., Suki, W.N., & Jackson, D. (1980). Hypercalcemia - etiology, manifestations, and management. Heart and Lung, 1, 146-151.

APPENDIX A

EXPLANATION OF THE STUDY AND OF THE CONSENT FORM

My name is Doris Coward. I am a graduate student in nursing at University of California, San Francisco (UCSF). I am conducting a study to determine the knowledge of cancer patients about one of the complications of cancer. May I talk to you about my study?

One of the complications caused by certain types of cancer is an increase in the mineral calcium circulating in the bloodstream. A large increase in calcium in the bloodstream can cause a patient difficulties which are unrelated to the cancer itself. This condition is called hypercalcemia. If hypercalcemia is promptly diagnosed, treatment can reverse its symptoms.

It is important that patients who are at risk for the development of hypercalcemia understand the condition, its symptoms, and how to possibly prevent it. Before I, or someone else, can plan ways to teach those things to patients, we need to know what patients already know.

If you agree to participate in my study, I will ask you to help me complete a questionnaire that will take about ten minutes. The questionnaire will assess your level of knowledge about hypercalcemia.

Your responses on the questionnaire will be confidential and your name will not be used in reporting the results.

You are free to decide to participate or not to participate. The care you will receive here will not be affected by whether you do or do not participate in this study.

Are you willing to participate? If yes, I would like you to read this consent form. It summarizes the information I have just given you and tells you your rights as a participant in this study. After you read and sign it, we can begin the questionnaire.

After we complete the questionnaire, I would be happy to answer any questions you might have about hypercalcemia.

APPENDIX B

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CONSENT TO BE A RESEARCH SUBJECT

Doris Coward is conducting a study on patients at risk for developing cancer-induced hypercalcemia. The purpose of this study is to determine the knowledge level of hypercalcemia in hospitalized cancer patients who are at risk for developing hypercalcemia.

If I agree to participate, the following will happen:

> I will complete, with Ms. Coward, a questionnaire, which will take approximately ten minutes.

There is no risk or discomfort from taking part in this study except for the time spent in completing the questionnaire.

There will probably be no benefit to me unless receiving information about hypercalcemia in this manner helps me to better manage this condition should it happen to me. It is hoped that the results of this study will help to decide how to give information to future patients.

All information will be kept as confidential as possible, and my identity will not be revealed to anyone or in any publications.

I have discussed this study with Ms. Coward, and my questions have been answered. If I have any other questions, I may call Ms. Coward at (415) 493-7158,

My participation in this research is completely voluntary. I am free to withdraw from this study without it affecting my care here in any way.

Date	Subject's Signature
CHR Approval Number	Subject's Phone Number

APPENDIX C

STANFORD UNIVERSITY HOSPITAL INFORMED CONSENT

You are invited to participate in a study of patient knowledge of hypercalcemia. I hope to determine the level of knowledge of cancer patients about this complication of certain types of malignancy. You were selected as a possible participant for this study because you have a type of cancer which sometimes causes hypercalcemia. It is hoped that the results of this study will help to decide how to give information to future patients.

If you decide to participate, you will complete, with the assistance of Doris Coward, a questionnaire which will take approximately ten minutes.

There is no risk of discomfort from taking part in this study except for the time spent in completing the questionnaire.

There is probably no benefit to you unless receiving information about hypercalcemia while participating in the study helps you to better manage this condition should it happen to you. I can not and do not guarantee or promise that you will receive any benefit from this study.

Any data that may be published in scientific journals will not reveal your name. In the interest of public safety, patient information will be provided to federal and regulatory agencies as required.

Your decision whether or not to participate will not prejudice you or your medical care. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice to you or effect on your medical care.

If you have any questions, I expect you to ask me. If you have any additional questions later, Doris Coward, at (415) 493-7158, will be happy to answer them.

For further information, please call 497-5244 or write the Medical Center Committee for the Protection of Human Subjects at 851 Welch Road, Room 115, Palo Alto, California 94304. In addition, if you are not satisfied with the manner in which this study is being conducted, you may report any complaints to the same telephone number and address.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR, AND THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED. A COPY OF THIS FORM IS AVAILABLE TO YOU UPON REQUEST.

_____ Date _____

Signature

_____

Signature of investigator

APPENDIX D

HYPERCALCEMIA KNOWLEDGE QUESTIONNAIRE

Part I. Demographic Information

1. Subject code number _____
2. Age _____
3. Sex _____
4. Race _____
5. Education - highest grade completed _____
6. Occupation (or former occupation) _____
7. Medical diagnosis other than cancer _____

_____

8. Cancer diagnosis _____
9. Length of time since diagnosis _____
10. Health supervision _____
11. Cancer treatment patient has received or is receiving

    a) surgery _____ c) chemotherapy _____
    b) radiation _____ d) immunotherapy _____

12. Has the patient ever experienced hypercalcemia? _____
13. Medications patient is taking _____

_____

14. Date of interview _____
15. Performance status using AJCC Performance Status Scale _____

Status	Definition
0	Normal activity
1	Symptoms, but ambulatory
2	In bed $<$ 50% of the time
3	In bed $>$ 50% of the time
4	100% bedridden

Part II. Knowledge of Hypercalcemia

1. a) Were you aware of the condition called hypercalcemia before this researcher mentioned it to you? Yes No

   b) If yes, what can you tell me about hypercalcemia?

   _____

   _____

   c) Had you been told previously that hypercalcemia might occur in you as a complication of your cancer? Yes No

   d) If yes, who told you? _____

2. a) The following are the symptoms a person with too much calcium in his/her bloodstream might experience. Have you been told that you might at some time experience any of these symptoms?

Nausea and vomiting	Yes	No
Muscle weakness	Yes	No
Severe fatigue, lethargy	Yes	No
Severe thirst	Yes	No
Large increase in amount of urine	Yes	No
Mental confusion	Yes	No

   b) Were you aware that these symptoms might occur suddenly? Yes No

   Were you aware that they might develop over a longer length of time (several days to two weeks)? Yes No

   c) If you were told about the above, what were you told to do if you experienced any of those symptoms?

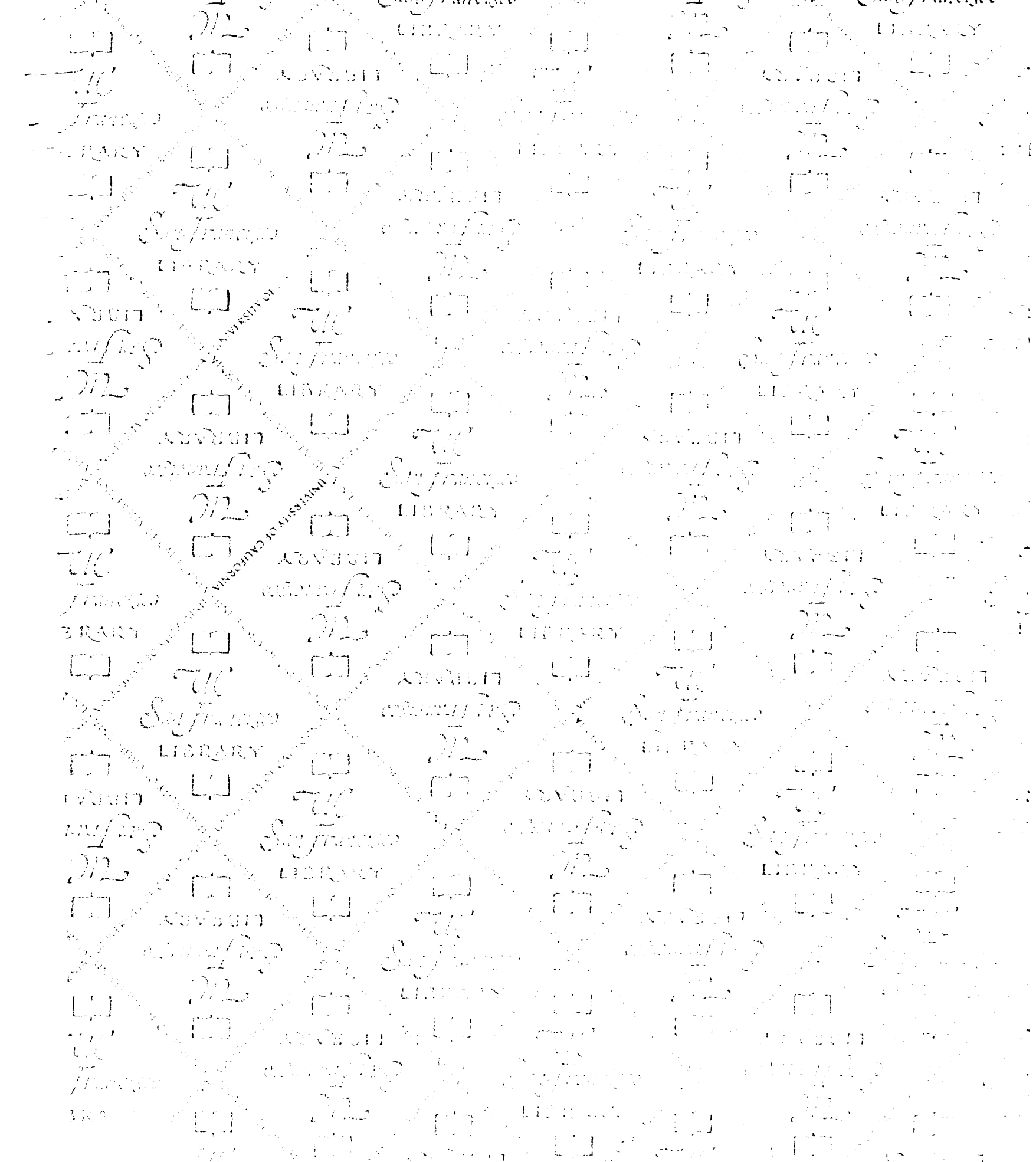
   Call the doctor _____ Not told _____
   Call the nurse _____ Other _____
   Call the clinic _____

3. There are two measures a patient might take to help prevent hypercalcemia. These are to drink an adequate amount of liquids and to stay as mobile as possible.

   Did you know to do these things? Yes No
   Who told you to do them? _____
   Did they tell you why you should do them? Yes No

4. How often do you have blood tests drawn? _____

   When you have blood drawn, is your calcium level checked? Don't know Yes No


UNIVERSITY OF CALIFORNIA
LIBRARY