PEDIATRIC ONCOLOGY:
AN EDUCATIONAL
HANDBOOK

by

Dawn Louise Gormely

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of a project submitted by

Dawn Louise Gormely

This project has been read by each member of the project comittee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

Ardella Fraley, M. N., R. N. Ardella M. Fraley (Signature) 4-11-96 Date

Approved for the Department of Nursing

Kathleen H. Chafey, Ph. D., R. N. Kathleen Chafey (Signature) May 6, 1996 Date

Approved for the College of Graduate Studies

Robert L. Brown, Ph. D. R L Brown (Signature) 7/8/96 Date

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Signature Dawn L. Gormely

Date 4-25-96

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ABSTRACT

In rural areas, such as Montana, nurses are faced with the challenge of initiating patient and parent education for pediatric oncology families during the extremely stressful time of diagnosis. The short period of interaction a rural nurse has with a pediatric oncology family prior to transport to a tertiary center for treatment requires consistent and concise provision of basic knowledge required to survive the next few days. It is estimated that only 10% of initial discussions regarding diagnosis and treatment is retained by those involved, indicating the need for written materials that can be reviewed at at later time. The inconsistency in teaching content and lack of written educational materials regarding Pediatric Oncology for parental review is a current problem at St. Peter's Community Hospital (SPCH) in Helena, MT.

To resolve this gap in patient and parent education, several handbooks, books, and articles related to Pediatric Oncology were reviewed to produce an educational handbook for use by the nurses at SPCH. An extensive review of learning theory was utilized in the preparation of the text.

The resulting handbook is a loose-leaf, three ring notebook with tabbed sections. The loose-leaf format allows content to be individualized to the specific child's disease and treatment. The text is written in simple conversational style with the overall readability at the sixth grade level. Each main topic is divided into appropriate subheadings and blank space is available in each section to personalize the information to each family.

CHAPTER 1

INTRODUCTION

Background and Focus of the Project

Pediatric Oncology in the rural setting poses many challenges to both the health care provider and the family who must face such a diagnosis. The diagnosis of cancer in a child living in a rural setting means referral to a tertiary center for diagnostic evaluation, and initiation of a treatment protocol. Although referral for the initiation of treatment is inevitable, the rural health care provider must begin educating the family about the disease, and provide the basic information on which the family can later build.

Having a child diagnosed with cancer is a devastating experience for a family that elicits many emotions, for both family and the health care provider. This initial period of diagnosis is filled with significant stress, during which time most families can absorb only the essential and basic information. It is estimated that only 10% of the initial discussion regarding diagnosis and treatment is retained by those involved (Brown, 1989; Eden, 1994). Emphasis on the events that they may anticipate in the first 24 to 48 hours should be the primary focus of the rural health care provider working with a family in preparation for referral and transport to a tertiary center. It is important to give accurate and adequate information to allow for decision making and informed consent, but hearing about specifics that may occur two to three months later is usually a source of confusion for families during this initial period (Conaster, 1986). The initial education

should primarily be directed to "survival" knowledge or skills that will help families get through the most difficult time: orientation to the medical world, its' hospitals, terminology, tests and procedures (Kramer-Fireman & Perin, 1985; Ruzicki, 1989).

Currently at St. Peter's Community Hospital (SPCH) in Helena, Montana, the initial education for the families with a child newly diagnosed with cancer is at the discretion of the nurse on duty at the time, with no guidelines for staff or written materials for families to review. This leads to fragmented and incomplete information delivery to the family, as well as frustration for the nurses involved. Additionally, the lack of printed materials for parental review is a missed opportunity to provide the family with the means to review the content of conversations during the initial period of diagnosis.

The common knowledge base shared by the family and the health care provider is the foundation for subsequent education and support in caring for the pediatric cancer patient (Pass & Massicotte-Pass, 1987). With this in mind, it is important that the local health care providers be consistent in the content of the initial teaching, and provide written information to the families for review. This initial contact with the family is a time of trust building as well. Many families will return to their communities where portions of their prescribed cancer treatment can be done, but only done well if there is a positive relationship between the family, the local providers, and the tertiary center physicians (Lozowski, Chesler, & Chesney, 1993).

The lack of a consistent resource leads to the focus of this project, which is to produce an educational guide for those faced with the care of a child diagnosed with cancer. The goal of this project is to provide the staff at SPCH written materials that will be consistent and available for use by all staff to begin educating a family in cancer treatment. The content of this packet may be copied and distributed for parental review.

Significance to Nursing

Nursing in large urban hospitals, such as Primary Children's Hospital in Salt Lake City, allows the nurse to focus on one speciality area and learn that practice well. The nurse in a rural Montana hospital may be hired for a specific clinical area, but must be able to go wherever needed within the facility (Johnson & Barba, 1992). In other situations, previous specialty units are being combined with other units due to low patient volume, for example, a combined surgical-pediatric unit such as is the case at SPCH. For the nurse working in the rural areas any shift may bring the need to deal with situations less familiar and sometimes stressful, such as working with a child and family with a new diagnosis of cancer.

Education is continually needed to update and prepare the nurse generalist to meet with the varied challenges of daily rural practice; however, such continuing education can be difficult to obtain. Barriers to such education include distance, economic factors, and staffing issues. Many rural hospitals cannot afford to provide workshops or financially assist the staff to travel to areas where workshops may be held, and the low volume of certain types of patients does not present the nurse with enough experience to maintain expertise (Johnson & Barba, 1992).

Because nurses are professionals, they are responsible to the public for the services rendered by their peers. As professionals, nurses assume a duty to practice in accordance with established standards and to improve standards as knowledge increases (American Nurse's Association, 1976, Statement No. 8, as cited in Curtin & Flaherty, 1982). One of the most effective ways to promote excellence in nursing practice and to provide information is for nurses to offer support, guidance, and direction to one another.

To neglect or refuse to offer this kind of assistance constitutes a breach of faith with both colleagues and the public because it will negatively affect the quality of nursing care provided. Nursing as a caring profession involves not only education and care for and of patients, but also for and of fellow nurses (Curtin & Flaherty, 1982).

Providing a written reference guide for St. Peter's Community Hospital will make available a resource for sharing of information related to pediatric oncology among the nursing staff. This will allow each nurse to broaden his or her clinical knowledge base and be more prepared for the responsibility of preparing a family for cancer treatment. The handbook will also provide an effective method of teaching the parents of a child with cancer. Such methods are increasingly important in a cost-containment environment and as the trend for home care increases. The benefits to nursing include increased parental involvement in care, improved parental coping, and enhanced learning for other care providers (Heiney & Wells, 1995). Additionally, it will provide the author with the opportunity to share a portion of her knowledge of pediatrics and oncolgy with her peers in hopes of assisting them in their professional development.

CHAPTER 2

LITERATURE REVIEW

Many will agree that patients and their families need assistance with understanding their health situations and in making health care decisions. As a result, patient and family education has become an integral part of cost-effective, quality health care. It is important for those providing care to understand teaching as a tool of health care, what education is expected to accomplish, and the many ways a provider can function as a teacher (Redman, 1993). Having this in mind, the literature review for this project includes general adult and child learning theory, nursing roles, and teaching methods pertaining to patient/parent education in the pediatric oncology setting.

Historical Development

The concept of patient/parent education has changed over the last fifteen to twenty years from casual, impromptu, and fragmented experiences to planned educational programs. Johnson and Flaherty (1980) recognized that patient/family education is any combination of learning opportunities designed to affect the knowledge level, skills, attitudes, or other behaviors of patients and their families. The goal of such education is to assist patients and their families in being knowledgeable participants in their own health care. Although the majority of pediatric health care providers have

always involved parents in their child's care, family participation has become even more important as cancer treatments have become more complex and demanding.

Over the last two decades of growth, several events have made patient/family education a visible concern. The Helsinki Conference set forth the elements of informed consent. (Kramer-Fireman & Perin, 1985). It became obvious that to truly obtain informed consent, patient/family education was a realistic method to enable understanding about health care options.

A second tide of events that influenced patient/family education was the consumer's movement. In 1972, The American Hospital Association published the Patient's Bill of Rights, which states that the patient has a right to know and understand his or her disease and treatment, and the medical and nursing professions are responsible for providing the necessary information (as cited in Redman, 1993). It had already been accepted practice in the area of pediatric oncology to provide extensive information to parents about the often experimental protocols used to treat their child's cancer (Kramer-Fireman & Perin, 1985; Redman, 1993). The information was shared with the intention of increasing cooperation of the family during treatment, and the Patient's Bill of Right's cemented that responsibility for all patients, adult and pediatric alike.

More recently, the health care crisis this country is experiencing, and the shrinking health care dollar, has renewed the interest in patient/family education. Shorter hospital stays and the increased incidence of long-term illness and disabilities have necessitated patient and family education to achieve effective participation in patient care and treatment (Redman,1993). It is hoped that more knowledgeable consumers will take responsibility for their own health, lead healthier lifestyles, and be proactive when undergoing treatment for illness. Education is the key to shifting the responsibility of health care decisions from the provider to the consumer, and this self-care will lead to decreased cost due to hospitalization.

In the early 1970's, Futterman and Hoffman (as cited in Merriam, 1993) observed several adaptive behaviors among parents which helped them cope with their child's life-threatening disease. A diagnosis of cancer evokes parental feelings of inadequacy and powerlessness. Many parents will respond by attempting to gain back the lost control through knowledge of the disease. Once the initial shock of the diagnosis has partially subsided, the parents are often highly motivated to learn not only about the disease, but how to facilitate treatment and manage the side effects.

Review of Learning Theory

Learning involves change. The change may be new thinking strategies, new motor skills, or new attitudes that promote a desired performance. General conditions such as reinforcement are applicable to all kinds of learners. Learning theories of this century may be classified into the broad categories of behavioral and cognitive (Redman, 1993).

Classic behavioral learning theory involves the conditioning or reinforcement of behavior. Motivation or stimuli for behavior change generally arises from environmental events. Changes in responding occur through a process known as conditioning. Most behaviorists recognize two types of conditioning: classical and operant. Classical conditioning involves a process of learning in which a stimulus that elicits a desired response is paired with another stimulus that does not initially cause a similar response (a neutral stimulus). After associating the two stimuli for a period of time, the formerly neutral stimulus will elicit the desired response alone (Redman, 1993).

The relationships between behaviors and their consequences are the focus of operant conditioning. A number of techniques are used to increase or decrease desired behavior. Positive reinforcement, which may be a reward or the removal of an aversive

agent, used following a desired behavior increases the probability that the behavior will be repeated under similar circumstances. Reinforcers may be such things as food, warmth, praise, recognition, pay, or grades, and the effects will vary from one individual to another. Punishment delivered immediately in response to a behavior may decrease that behavior; however, the results of punishment are unpredictable.

It is important in teaching to assure effective reinforcement is applied to a defined behavior so the learner will understand what conduct warranted the reward. As the desired behavior is learned, reinforcement is frequent, but after the behavior is established, the reinforcement is given randomly to encourage persistence in that behavior.

In cognitive theory, learning is seen as the development of insights or understandings that provide a guide for behavior. Cognitive learning styles are information processing habits that represent a learner's usual way of perceiving, thinking, problem solving, and remembering (Flannery, 1993). Individuals vary in their preferred methods of processing information, and new insights may lead a learner to adapt and reorganize their cognitive structure to meet the needs of a situation. Within this framework, learning makes change possible, and motivation to learn results from the need to understand the world and solve problems (Redman, 1993).

More recently, the social cognitive theory of learning has evolved. This theory is largely cognitive in origin, but also incorporates principles of behaviorism. According to Bandura (1986), humans respond primarily to cognitive representations of the environment rather than to the environment itself. Individuals acquire information, values, attitudes, moral judgments, rules of behavior, and new behaviors by observing others. This information serves as a guide for future action or responses. Through this type of learning, the individual also obtains information about the likely consequences of an action (Merriam, 1993).

In social cognitive theory, behavior is said to be initially regulated by extrinsic incentives in the early stages of developing competencies until competency becomes self-rewarding. Much of an individual's behavior is considered to be motivated and regulated by internal standards, self-evaluation, self-incentives, self-concept, and the belief in one's ability to realize a certain level of performance (Redman, 1993).

Adult Learning.

To understand the adult learner, one must certainly take into consideration the learner, the learning process, and the context. No single perspective, theory or model provides a comprehensive picture of adult learning. One of the first attempts at defining adult learning, known as andragogy, was introduced by Malcolm Knowles approximately twenty-five years ago (Merriam, 1993). Andragogy, or the study of teaching adults, sets forth certain conditions for adult learning. Firstly, there must exist an atmosphere that promotes collaboration, mutual trust, respect, and support. Secondly, the learner must participate in defining their needs, formulating objectives, designing and carrying out plans, and evaluating their learning (Redman, 1993). Knowles' more recent work reflects that pedagogy (child learning)-andragogy represents a continuum ranging from teacher-directed to student-directed learning and that both approaches are appropriate with adults or children depending on the situation. For example, adults who know little or nothing about a subject benefit from teacher-directed instruction until they have enough knowledge to begin directing their own learning. While andragogy does not define the uniqueness of adult learning, it does provide guidelines for designing instruction with learners who are more self-directed, and self-motivated. Knowles, along with several other educators have focused on the concept of adults being self-directed learners.

Grounded in the notion that adults are independent and thus self-directing, this line of inquiry is almost exclusively adult oriented (Merriam, 1993).

A second major idea in distinguishing adult education from pre-adult education is illustrated by Mezirow's theory of perspective transformation. Within this theory, adult education is described as any organized and sustained effort to facilitate learning, especially in a way that enhances the adult's capacity to function as a self-directed learner (Redman, 1993). Focus is on the dramatic changes in the individual learner that can occur when adults engage in learning transaction. Transformational learning is linked to development or change, that is most often in a positive, growth enhancing direction (Merriam, 1993). The challenges of adulthood are seen as involving a process of traveling through an uncertain amount of change that transforms the individual into conformity within the society's perspective of normalcy. This process may involve a series of changes, although a disorienting dilemma is clearly a factor in motivating a transformation. The passage into new ways of dealing with a situation involves difficult negotiation, compromise, stalling, and backsliding. Self-deception and failure are common during the process of transformation, but through the adult capability to be critically reflective, perspective change occurs. Health situations frequently cause individuals to feel disoriented and precipitate such self-reflection (Redman, 1993).

Learning in Children.

Pedagogy, or the art and science of teaching children, is based on the early practice of teaching that required obedience of children, who were dependent on their teachers to tell them what they needed to know. In this content model, it is the teacher who decides what is to be learned, arranges how it will be presented, and selects the means by which it will be taught (Long, 1984).

Developmental theory is an important key to teaching children. Several experts have proposed schema to describe how children learn. Bruner (as cited in Lall & Lall, 1983) describes the three stages of action, imagery, and symbolism, and the idea that a child can learn anything if led through these stages. Bloom and Montessori (as cited in Lall & Lall, 1983) emphasized the importance of early environment in the development of a child's intelligence. Montessori also believed that the child learns through individual initiative and self-direction, and stressed that the teacher should help structure the environment by providing a variety of learning materials and methods. Erikson and Piaget (as cited in Edelman & Mandle, 1994) describe stages of development which give definition to phases of growth and development in regard to tasks. Kohlberg's cognitive-developmental approach (as cited in Edelman & Mandle, 1994) is useful in defining attitudes, values, and morals. Each of these theorists have added significant concepts to the knowledge base of growth and development and child learning.

Knowledge of growth and development suggests that teachers should determine realistic objectives and explain them in a way a child can understand. All children pass through the same developmental and learning stages; however, individuals progress at their own rate within a particular stage, and a child's background and environment determine the pace at which learning occurs (Lall & Lall, 1983). Ability to learn depends on maturation, and a great deal of maturation occurs in childhood. The level of maturity determines a child's ability to absorb information. Knowing a child's maturity level can help determine the objectives and teaching strategies for that child (Redman, 1993).

The most significant dimension of a child's development is the degree of differentiation he or she makes between self and others. As a child grows, he or she moves toward a clearer distinction between the internal and external self and becomes less egocentric. Intellectual development, as described by Piaget, moves from concrete to

abstract. It is important to remember that children learn by listening and looking, and express themselves by talking and doing (Redman, 1993).

Domains of Learning.

Learning objectives and behaviors have been classified into three domains. The first is cognitive learning, which involves the intellectual skills necessary for understanding and acquiring facts, concepts, or problem-solving skills. The second domain is affective learning, which entails formulating and expressing feelings, values, attitudes, and beliefs. Lastly, psychomotor learning involves acquiring motor skills that call for neuromuscular coordination (Kramer-Fireman & Perin, 1985; Redman, 1993).

Cognitive learning can be viewed through a taxonomy of educational objectives with behaviors defined and ordered in terms of complexity. Early learning centers around information recall, followed by comprehension, application, analysis, synthesis, and evaluation. Redman suggests that facts and concepts basic to cognitive learning are commonly taught by lecture and discussion, audiovisual aids, and written materials. Attainment of the higher categories of the domain requires much more investment of time and energy on both the part of the teacher and the learner, with the learner actively working through the problems and the teacher assisting the learner to attain insight into the process.

Affective learning does not automatically follow once facts are learned, nor does it lend itself to a didactic presentation. Methods such as counseling, guidance, and support are preferred since they encourage the discussion of feelings and reactions. Affective learning may also be enhanced by direct role modeling or participating in support groups, both which provide opportunity to learn from others approaches and experiences (Kramer-Fireman & Perin, 1985). A proposed taxonomy for this domain

includes receiving or becoming aware of a situation, responding to the situation, valuing it, and finally organizing it (Redman, 1993).

Psychomotor skills are taught in three basic phases. The first or cognitive phase requires the learner to observe a demonstration and listen to verbal explanations of the skill. Secondly, the organizing phase ensues, which involves practicing the motor skill until the sequence of steps becomes automatic. The final phase is that of perfecting the skill with noted continual improvement and mastery.

Principles of Parent/Patient Education.

Regardless of learning goals or teaching methods, certain premises underlie patient and parent education. DuGas (as cited in Kramer-Fireman & Perin, 1985) developed a framework for designing and implementing educational programs. The premises are based on the belief that certain conditions are more conducive than others to the success of teaching-learning endeavors. This is highly applicable to the pediatric oncology population.

Learning is more effective when it is in response to a perceived need. Some parents may respond immediately to the diagnosis of cancer by seeking information about the disease and its treatment. Others may be in such a state of shock after hearing the diagnosis that they become immobilized, numb, overwhelmed, and even deny the reality of the situation.

There is a great variation in how much parents want to know and how much responsibility they can or are willing to assume. Some want very detailed information immediately, and others expect to be advised of the situation and directed in decision

making. Thus, each family must be treated individually for interest and ability in educative matters.

Active participation on the part of the learner is fundamental if successful learning is to take place. Learning activities should allow the parents to be active rather than passive participants in the educative process. It requires a dialogue between the provider and the entire family, and provides opportunities for visual, auditory, and hands on learning experiences.

Learning is facilitated when information to be learned is meaningful to the learner, and is made easier when the material to be learned is related to what the learner already knows. In the event of a diagnosis of cancer in a child, the family faces an enormous amount of new information. The content of materials should be individualized to meet each family's situation and broken down into small logical steps to build upon previous knowledge. Analogies may assist family members to assimilate complicated concepts. Material presented are most meaningful to parents if examples are drawn from their child's situation and if they understand how the information can be used in a practical way.

Learning must be reinforced. Repetition and reinforcement are essential principles in client education. Due to the high level of parental stress and sophistication of the information, content needs to be continually reviewed and updated (Eden, 1994; Heiney &Wells, 1995; Nathanson & Powers-Monaco, 1984). Parents need to be told that it is understandable, and it is expected that they will need to ask questions or hear explanations several times before understanding and recall takes place.

Environmental control is an often overlooked aspect of teaching; however, it is critical to the success of client education. The atmosphere should be characterized by comfortable seating, mutual trust and respect, freedom of expression, and acceptance of differences. The hospital, unfortunately, is not quiet, or conducive to periods of time free

from distraction. Initial education sessions in the hospital should be set up for times when the parents are able to concentrate on their own learning needs. A nonjudgemental atmosphere should exist so that parents can openly express their thoughts, fears, and feelings throughout the process. The setting must be nonthreatening to foster the development of mutual trust, respect, and cooperation.

Identification of Education Needs

Kramer-Fireman and Perin (1985) identify a framework for core educational content by distinguishing characteristic tasks, issues, and needs which predominate during sequential phases of the illness. The family's ability to meet these phase-related demands is directly related to their overall ability to integrate and adapt positively to the disease, treatment, and inevitable changes in life style. Education directed at each phase of the illness should enhance the family's ability to learn and cope with that stage. To more easily utilize this approach, Kramer-Fireman and Perin (1985) have divided childhood cancer into six critical phases. These phases include the pre-diagnosis, diagnosis, maintenance, completion of cancer treatment, relapse, and the terminal phase. For the purposes of this project, emphasis will be placed on the pre-diagnosis and diagnosis phases.

Pre-diagnosis

The first phase, the pre-diagnosis period, brings on many sudden changes, and families are faced with the unknown. A differential diagnosis that includes cancer initiates a crisis situation and response. The sudden hospitalization, numerous tests and

procedures, unfamiliar persons, disruptions to home and work schedules, and the uncertainty of the entire situation challenges even the most resourceful family.

The educational focus for this phase is on affective learning; therefore, initiating crisis and supportive interventions are essential. It is important for the nurse to quickly obtain some sense of the family dynamics, communication patterns, and coping styles. This initial information becomes the foundation for ongoing family assessments that will influence and direct all further interactions (Kramer-Fireman & Perin, 1985).

The term cancer also evokes such responses as anxiety, despair, anger, guilt, and fear. Because of the intense emotional response, it is difficult for any true cognitive learning to occur. Education should be directed primarily at survival knowledge that will assist families get through this most difficult time. Initial orientation to the hospital and its routines and staff should be done. Explanations of tests and procedures, how and why they are done, and what the results indicate are necessary points to cover. Parents also need anticipatory guidance regarding how best to support the child through the hospital experience and how to act as the child's advocate (Kramer-Fireman & Perin, 1985).

Diagnosis

Confirmation of the cancer diagnosis unleashes the crisis situation. The emotional response described in the previous phase is intensified. Parents are in a state of shock, disbelief, and possibly even in denial. Anticipatory mourning takes place as parents are faced with the potential loss of their child. During this phase, a combination of affective and cognitive learning takes place. It is the affective learning, however, that dominates the first several days when families need help managing their emotional reactions that interfere with their ability to listen and remember (Kramer-Fireman & Perin, 1985; Menke, 1986).

Parents need to be reassured that the information presented will be repeated again and again, and the informational exchange will continue throughout the child's treatment. Written and verbal reinforcement are necessary during the first several weeks of therapy to begin the process of cognitive learning, first by recall of information, and eventually by the more complex areas of cognitive learning.

Rural nurses who are faced with these first two phases of childhood cancer in the acute care setting need to provide the family with the survival skills necessary to get them through the initial days of diagnosis. Interventions that restore sense of control as capable adults and parents are critical. Solving problems around the care of other children, employment commitments, financial concerns, and telling the child, siblings, family and friends of the diagnosis are concrete ways to assist parents in regaining some control in their lives (Kramer-Fireman & Perin, 1985). Providing the family with basic factual information about the diagnosis, tests, and procedures is necessary in order for parents to give informed consent. Painting a picture of what will happen at a tertiary center as treatment is formulated, and what types of choices they may be asked to make, can assist them in coping.

Preparation of the parents is important, but it is also important to remember the child. Health care providers must begin to prepare the child for what to expect in the hospital environment so that coping behaviors can begin to develop. Parents should be involved in the preparation because it is they who the child trusts, and participation may also help reduce both the child's and the parent's stress level. Educational preparation is a process that must continue throughout the cancer treatment experience. Prior to any new circumstance, the parent, child, or adolescent requires additional preparation specific to that situation. Another aspect of preparation is the development of relationships between the family and the care providers. The entire family needs to have trust and confidence in

those who will be performing the tests and procedures during the diagnosis and treatment of their child. (Menke, 1986).

Implementation of Parent/Patient Education

The central content of information presented should be modified to meet the needs of each family's unique circumstances and needs. To individualize the process, it is necessary to assess the ability and readiness of the learner, as well as choose appropriate methods to achieve maximum learning. Equally important is ongoing evaluation of the teaching-learning process.

Assessment of the Learner

Educational assessment is similar to other nursing assessment. It is a continuous process that involves observation, listening, communication skills, and discussions with other health care providers and family members. A great deal of information can be gathered while providing routine nursing care (Ruzicki, 1989).

Many factors must be considered when assessing the learner, while realizing not all families need the same instruction, nor will all be ready to learn. What rural families facing referral to a tertiary center need to know can best be determined by considering what they must comprehend to survive the present and upcoming hospital experience. The need for teaching may be evident through direct requests, by observation of a patient or family, or in anticipation of the treatment plan (Redman, 1993; Ruzicki, 1986).

It is important to determine who comprises the family, who will be involved in the care of the child, and who will be responsible for decision making. Socioeconomic

status, as well as intellectual ability, educational background, and the ability to read are factors to evaluate when teaching information regarding disease processes, treatments, or complicated skills (Kramer-Fireman & Perin, 1985; Menke, 1986).

Sociocultural issues are another area that require attention. What language does the family speak? What is the cultural orientation of the family? Many cultures define who will take charge of learning new knowledge, but this individual may not be the primary caregiver to the child. Other cultures define the role of the family as dependent upon the hospital staff and expect the health care providers to make all decisions and provide care (Kramer-Fireman & Perin, 1985).

Readiness to learn is another area that requires assessment. Many factors contribute to educational readiness. Physical symptoms such as pain and fatigue, psychological aspects such as motivation, attitude, health beliefs, emotional response, and stress all affect the ability of patients and families to learn. Parental perceptions and expectations of what is to be learned and how they will apply the knowledge is also an area requiring assessment. Some parents feel it is not within their ability to interpret laboratory results, or learn how to calculate drug dosages. In contrast, others may, after learning the basic knowledge of the disease and treatment, make decisions regarding changing drug dosages, or holding chemotherapy due to low blood counts (Kramer-Fireman & Perin, 1985; Ruzicki, 1989).

Collectively, these factors influence how much information can be given and at what level. Assessing the circumstances and the learner and incorporating that knowledge into a teaching plan requires the health care provider to get to know the patient and family, communicate openly and effectively, and continually reassess as teaching and learning proceed during the child's treatment (Kramer-Fireman & Perin, 1985).

Selection of Teaching Methods

Selecting the appropriate method for teaching is an integral responsibility of the nurse working with the pediatric oncology patient and family. With a thorough knowledge of the information to be learned, an assessment of patient/family needs, and a realistic view of the time constraints and setting, the nurse can choose the most appropriate methods for teaching patients and parents.

Verbal Instruction. A majority of teaching can occur through interpersonal interaction. This interaction can be formal and structured or, as it often is in pediatrics, less formal, such as sitting at the bedside talking with parents. The advantage of this teaching process is the one-on-one interaction which allows for constant feedback from the learner to the teacher. The disadvantage is that the nurse may not be available when the parents want or need to talk, and frequent repetition is essential, which requires considerable nursing time (Fireman-Kramer & Perin, 1985).

Group sessions are well suited to patient education, as being part of a group may enrich the learning experience by allowing individuals to learn from one another as well as from the teacher. This method is also economical when several families can be taught the same information at the same time. The combination of lecture and discussion provides the group with the information and allows for response in the form of comments, questions, and emotional reactions (Fireman-Kramer & Perin, 1985). Disadvantages of this teaching format include the small number of families requiring information regarding pediatric oncology in rural settings at any given time, one member dominating the group, and extraneous discussions diverting the groups efforts from the task at hand (Stanhope & Lancaster, 1984).

Written Material. Printed teaching materials can be defined as "static language that discusses a topic, provides limited feedback, and is constantly available for review" (Kramer-Fireman & Perin, 1985, p. 45.). For most parents, pediatric oncology handbooks, pamphlets, and brochures can be an excellent adjunct to other methods of learning. Written materials can be used to prepare for a verbal teaching session, enhance verbal exchange, and provide a consistent source for review.

The advantage of printed material is that it is readily available and consistent in message. Patients, parents, and family members can read and re-read it to achieve new or higher understanding. It can be used any time and any place that is convenient for the learner. The obvious disadvantage is that all parents may not be literate or able to read at the level the materials are written. Each individual has his or her own preferred style of learning, so written materials may not be a comfortable method of obtaining information for some. If printed material is not accompanied by another teaching method, the learner will not receive feedback or evaluation of comprehension (Kramer-Fireman & Perin, 1985; Redman, 1993; Ruzicki, 1989).

Visual and Audiovisual Materials. Audiovisual teaching methods encompass the use of both verbal and pictorial methods of material presentation. In the television oriented society, it may be a familiar and preferred method of learning by many parents. Advantages include the ability to review the material several times, the use of two senses to facilitate learning, and the presence of an instructor is not required for viewing. The availability of special equipment, the cost of material production, and the absence of exchange between the teacher and the learner are a few of the weaknesses of utilizing this method exclusively (Stanhope & Lancaster, 1984).

Examples of visual and audiovisual resources include pictures, posters, dolls, models, audiotapes, slide-tape presentations, movies, and videotapes. Utilizing these media in presenting material are useful and augment verbal interactions just as do written materials.

Self-Paced Modules. This type of information delivery relies heavily on written materials, although it is often accompanied by pictures and diagrams. Written sequential learning steps require the learner to answer questions about the material with immediate feedback provided. Programs may be either computerized or written in a booklet format (Redman, 1993). The learner controls the pace of the learning and can review material at any time.

This learning situation requires motivation on the part of the learner. Often materials are difficult to locate, and oversimplification of complex information occurs. Strengths of self-paced modules are that they provide immediate feedback and can be utilized any time, any place, and repeated as necessary.

Demonstration and Practice. This teaching method requires a skill or procedure be demonstrated to the learner. After the demonstration, the learner practices the skill step-by-step and then repeats the demonstration. This type of teaching is very effective when psychomotor learning is the primary goal of the session. It also has the advantage of providing immediate evaluation which allows for corrective teaching.

Re-demonstration is advantageous to parents because it allows them to integrate intellectual and motor skills necessary to master a task. The major disadvantage is the time required by the nurse to ensure mastery of the skill. In addition, each nurse may vary

the procedure slightly and thereby frustrate parents who are diligently trying to learn the correct practice (Kramer-Fireman & Perin, 1985).

Choosing Teaching Methods for the Child

The way a child is taught depends upon his or her cognitive ability. The young child who is in the preoperational stage of cognitive development has difficulty understanding abstract ideas, dimensions of time, and imagining the order of events when presented verbally. Furthermore, a child at this level of development has a short attention span, so education should be delivered in short sessions. It is also common for children when ill or stressed to experience some regression in their development, so this must be considered when choosing a method of presentation. Education can be facilitated by actual demonstration on a doll or a stuffed toy to show what will happen. Books, pictures, and play can be used as media to help prepare a child for procedures. It is important to limit each session to just one situation at a time. In addition to the presentation of facts, the types of sensations the child may experience and the feelings he or she might have need to be described (Menke, 1986).

The school-aged child in Piaget's concrete operational stage of cognitive development can be taught similarly to the younger child. This age group has a more realistic perception of time and can mentally order a series of events. Books and games can be useful media to utilize in educating the school aged child. A child of this age can understand terms related to his or her body, but does not always understand the location or function. Pictures and diagrams of the body can facilitate understanding of what the cancer is affecting within his or her body, and what will be done to help the body get better (Menke, 1986).

The adolescent can be taught similarly to an adult, since he or she is in the formal operations stage of cognitive development. Books, pamphlets, and demonstrations are helpful in preparing the adolescent. The adolescent, as well as the younger child, should be encouraged to express affective feelings about the situation and the information presented (Menke, 1986).

Evaluation

Evaluation determines the worth of something by judging it against a standard, and can serve several purposes. It can direct and motivate learning because it provides evidence about accomplishments. Evaluation reinforces correct behavior on the part of the learner and helps teachers determine the adequacy of their teaching (Redman, 1993).

Evaluation of patient education is necessary to provide not only information about the individual learner's progress, but also the program itself. The program evaluation is necessary to provide direction for improvement of content and delivery methods. Like teaching, evaluation is an ongoing process, and can be accomplished through requesting verbal or written feedback via rating scales, checklists, or by direct observation (Kramer-Fireman & Perin, 1985; Redman, 1993).

Proponents of patient education have attributed many positive outcomes to the education process including patient compliance, more appropriate use of health care services, fewer hospitalizations, and shorter hospital stays. Evaluation demonstrating these outcomes have often been inconclusive, or so limited in scope and design that outcome conclusions are inadequate. Kramer-Fireman and Perin (1985) identified several problems in regard to evaluation of patient education including the lack of personnel, funding, and difficulty in quantifying some outcomes such as coping, communication,

compliance, and attitude. The true effects of parent/patient education may be realized, and most measurable, after the child and parents are away from the treatment setting and predominantly involved in self-care. This is a time when they are less accessible to evaluation.

The use of ongoing evaluation throughout the teaching-learning process allows for identification of problem areas, which can be clarified immediately. Continuous evaluation through observation and discussion also reinforces successful skills and behaviors. Positive reinforcement during education sessions increases the confidence level of parents as they learn to manage necessary interventions outside of the hospital setting. This technique of ongoing evaluation is the most likely source of information regarding the success of educational interactions with parents of pediatric oncology patients.

CHAPTER 3

METHODOLOGY

The purpose of the parental education handbook is to begin the preparation of parents for initial hospitalization at a tertiary center as their child begins cancer treatment. The handbook utilizes extensive adult learning strategies. The content is a simple conversational style using second person with short, concise sentences. Every effort was made to use the same phrases and words, such as drug for medication.

Content was derived from a literature review relating to pediatric oncology educational issues as well as adult and pediatric learning theory. Efforts were made to identify what parents need to know in a given situation and materials were written to that need. As the content was being finalized, a field test of the material was undertaken. Hospital staff of the surgical-pediatric department at SPCH were asked to read and critique content, in order to provide feedback regarding necessary changes or additions. The staff input included editing and assistance in utilizing commonly understood terminology. Each of the six evaluations were positive for content and expressed satisfaction with the knowledge that the resource will be available for their use.

Considering 47% of American adults read below the eighth grade level, common words and words with two or less syllables were used when ever possible (Heiney & Wells, 1995). Medical terms were defined and abbreviations were explained prior to their use. Reading level was assessed through the application of the Gunning Fog Index (1968), the Flesch Formula (1974), and through SMOG testing (as cited in Stewart, 1996). These indexes were applied to the materials and results averaged to obtain the

reading ease. Each topic was assigned a corresponding grade level through this process. Flesch (1974) defines sixth grade level as "easy", seventh grade as "fairly easy", and eighth grade as "standard". Appropriate revisions were made according to the reading level assessment to maintain an overall sixth grade level. Recommendations from the field trial were also incorporated into the final draft of the written materials. Revisions suggested by the participants involved in the field trial were primarily centered around wording changes. These suggestions helped bring the average readability of the handbook to the sixth grade level.

CHAPTER 4

PROJECT OUTCOME

Results

The resulting parent education handbook is a loose-leaf, three ring notebook with tabbed sections (Appendix A). The loose-leaf format allows the materials to be photocopied, therefore, providing content that is individualized to the specific child's disease and treatment.

All copy is printed in black on white paper. The use of white spaces between lines and bold headings gives the eye a rest and helps divide content (Boyd, 1987). Blank lines and wide margins are present within the text to allow the nurse to personalize the information. Drawings and photographs are placed next to the related idea in the text. Bold and italicized print is used to highlight main headings and important ideas for ease of location.

Implications for Nursing and Recommendations

The development of this handbook has great significance to nurses in rural areas who are faced with educating a family during a tremendously stressful time. The handbook is a time-saving tool and an effective method of teaching the parents of a child with cancer. Such methods are increasingly important in a cost-containment

environment. As the trend for shorter hospital stays and the trend toward home care increases, beginning the education process early is a necessity (Heiney & Wells, 1995). Providing knowledge to families affected by childhood cancer allows for increased parental involvement and responsibility. Education also offers improved family coping skills, and the information learned can be shared with other caregivers such as grandparents, and day care providers.

Recommendations for continued success in educating Pediatric Oncology families includes an annual review and update of this handbook incorporating the input from staff and families who have utilized the resource. Knowledge regarding cancer and cancer treatment is an ongoing, ever-changing field; therefore, it is important to stay abreast of changes, and provide the most accurate information to parents and their children.

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APPENDICES

Appendix A

Pediatric Oncology:

An Educational

Handbook

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Introduction

This handbook is designed to provide initial information to families regarding childhood cancer and treatment. The information is basic and intended for the parents of newly diagnosed cancer patients. This resource will provide consistent information for families.

This is a time of significant stress, and *retention of verbal discussion is at best 10%.* It is very important to ***COPY*** all situationally pertinent pages of the handbook to give to the family in need. Providing handouts will give the parents the opportunity to review information and ask questions. Review the handout with the family and personalize them by writing between lines, in the margins, and highlighting important points. Remind them that this information will be repeated several times over the course of the next few days/weeks by the health care providers they will encounter. Encourage them to ask questions, and to write them down so as not to forget. Remember to include the child in the initial education process, keeping in mind his or her developmental level.

Financial Assistance

Local help is available to help defray costs of travel, meals and lodging while at tertiary centers.

1. The Gary Jacobson Memorial Fund is available to provide cash help to defray the unexpected cost of transportation and living expenses. Funds are obtained by calling Anne or Tom Jacobson. (*see p.39-40)*.

2. The Mandy Bell Endowment Fund was established for the purpose of aiding families who have children with Neurofibromatosis or other neurological illnesses. The fund provides money for the out-of-town travel expenses that families incur as they pursue treatment for their children. Children with Neurofibromatosis have first priority, and those with other neurological conditions have priority over any other type of medical condition. To make a request for assistance, call St. Peter's Community Hospital Foundation, 444-2370.

GARY JACOBSON MEMORIAL FUND



Gary Jacobson was diagnosed with neuroblastoma in August 1989 at 21 months of age. He subsequently died of the disease in December 1990. During the course of his illness, Gary and his family made eight trips to Salt Lake City for necessary, and at times, emergency treatment. The **Gary Jacobson Memorial Fund** was established by his family to benefit children with medical conditions requiring treatment at out-of-state facilities. The Fund is directed at, but not limited to, children suffering from cancer, heart problems, prematurity, burns and other chronic illnesses.

The expense of traveling to and from an out-of-state hospital is quite demanding on a family of limited means. Gas, meals and lodging add up rather quickly, not to mention airline tickets when the situation does not allow car travel. It is the function of this Fund to help defray these expenses for families in need. The dedicated individuals involved with the Gary Jacobson Memorial Fund believe that families traumatized with the illness of a child necessitating out-of-state medical care should not, and need not, be concerned about transportation and related costs.

In order for a family to qualify for financial assistance, the child needing out-of-town medical treatment must be 15 years old or younger; the family needs to reside within the Helena area (not necessarily limited to Lewis and Clark County) and the family must lack the financial resources needed to comfortably pay all anticipated travel-related expenses.

If your family qualifies, or someone you know qualifies, please contact any one of the Board members listed; help is on the way. Any donations to the Fund would be gratefully accepted and are tax-deductible. Information regarding donations may be directed to the individuals listed.

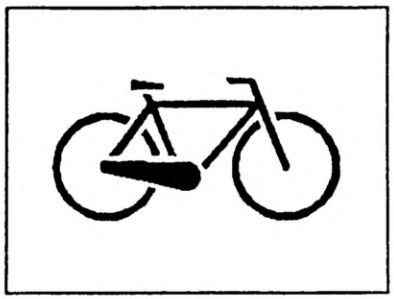
Gary Jacobson Memorial Fund
P.O. Box 122 ■ Elliston, MT 59728
406/492-6636
or
First Bank Helena

Board Members
Tom and Anne Jacobson, 492-6636
Carol Athearn, 443-1918
Nick Jacques, 443-5565
Ann Bullington, 443-7481



Please make your tax-deductible contribution to the Gary Jacobson Memorial Fund

GARY JACOBSON MEMORIAL, INC.
P.O. Box 122
Elliston, MT 59728



HELP IS ON THE WAY!

BOARD OF DIRECTORS:

Anne Jacobson	492-6636
Tom Jacobson	492-6636
Carol Athearn	443-1918
Ann Bullington	443-6200
Nick Jacques	443-5565

APPLICATION FOR ASSISTANCE

PARENTS:

Name _____

Address _____

Phone _____

CHILD:

Name _____

Birth Date _____

Diagnosis _____

Destination _____

Referring Doctor _____

Dollar Amount Needed _____

Intended Use of Funds _____

_____

_____

_____

Can Gary Jacobson Memorial, Inc. use your family name in future fund raising endeavors? YES _____ NO _____

_____ _____

(DATE) (SIGNATURE OF APPLICANT)

PLEASE GIVE A SHORT FINANCIAL STATEMENT ON THE BACK, like where you work, approximately how much you make and if you have other money resources.

TYPES OF CHILDHOOD CANCERS

Leukemia.

Leukemia is a cancer of the blood that develops in the bone marrow. The bone marrow is a jelly-like substance that fills the inside of bones. Its job is to make blood cells. The bone marrow makes three kinds of blood cells:

1. *Red blood cells* (RBC's or erythrocytes). These cells pick up and carry oxygen, and give blood its red color.
2. *Platelets* (thrombocytes). These cells help stop bleeding.
3. *White blood cells* (WBC's or leukocytes). These cells fight infection.

Leukemia begins from white blood cells. In leukemia, some white blood cells do not grow the way they are suppose to. Instead of aging and taking on their jobs, they stay young and continue to multiply. These young cells are called lymphoblasts or just "blasts" for short. This can happen to any of the three main types of white blood cells:

a. Neutrophils, which eat bacteria,

b. Lymphocytes, which make substances to fight bacteria, and

c. Monocytes, which destroy foreign materials.

When leukemic blast cells collect in the bone marrow, they crowd out the normal cells that grow there. Eventually, they take up so much room that the red blood cells, platelets, and normal white blood cells cannot be made. When this happens, symptoms start. If the red blood cells are crowded out by "blasts", the blood will be thin, which makes the patient look pale. Because the thin blood cannot carry enough oxygen to the heart, lungs, and muscles, the patient may also be tired. If the platelets are crowded out, bleeding problems and easy bruising may occur. If the normal, mature white blood cells are crowded out by the "blasts", there will be no cells to fight bacteria, and infections can occur. Other symptoms that may occur include fever, poor appetite, and arm, leg or joint pain.

Leukemia is not just one disease, there is truly a type of leukemia for each of the three major kinds of white blood cells (lymphocytes, neutrophils, and monocytes). Two of these kinds account for almost all childhood leukemias. They are:

Acute Lymphocytic Leukemia (ALL). ALL is the most common leukemia among the young. It is the most common occurring cancer in children. It affects the lymphocytes. Most children are between 2 and 8 years old when found to have ALL, but it can occur in people in their twenties and thirties too.

Acute Myelogenous Leukemia (AML). AML is also called acute granulocytic leukemia. It usually occurs in people over 25, but sometimes is found in teens and children. In AML, the "blasts" develop from cells that normally grow into neutrophils.

Diagnosis is done through testing bone marrow samples to see which type of white blood cell is the cause of the leukemia.

Treatment for leukemia is combination chemotherapy, where two or more anticancer drugs are used to kill the cancer cells. Blood transfusions and antibiotic therapy may also be needed.

Lymphomas.

Lymphomas are cancers of the lymphatic tissues, which make up the lymphatic system. This system is a circulatory group of vessels that carry lymph fluid,and lymphoid organs (lymph nodes, spleen, and the thymus) that produce and store infection fighting cells. Some parts of other organs like the tonsils, stomach, intestine, and skin have lymph functions. There are two general types of lymphoma:

Hodgkin's Disease. Hodgkin's disease is a cancer of the lymphoid tissue. It tends to involve the lymph nodes near the surface of the body, where the first sign of the disease may be a painless swelling in the neck, armpit, or groin. Other symptoms include decreased appetite, weight loss, tiredness, fever, and night sweats. Hodgkin's disease is most common in persons in their twenties and thirties and occasionally in teens. It is rare in children.

Diagnosis is made by lymph node testing

Treatment is primarily radiation therapy, however a combination of radiation and chemotherapy may be needed for children with wide disease.

Non-Hodgkin's Lymphoma. Non-Hodgkin's lymphomas are solid tumors with wide lymph node involvement. In children, this type of lymphoma most often occurs in the bowel and in the upper mid-section of the chest. It can occur in other organs like the liver, spleen, bone marrow, bones, lymph nodes, or the brain and spinal cord. Early signs of this disease depend on the site of the tumor, but may include stomach pain, constipation, breathing problems, cough, and sometimes fevers.

Diagnosis is made through a biopsy. A biopsy is where a piece of tumor tissue is removed and examined under a microscope. Once a diagnosis is made, many tests must be done to decide the extent of the disease.

Treatment consists of chemotherapy and radiation.

Central Nervous System Tumors (CNS Tumors). CNS tumors include brain and spinal cord tumors. As a group, brain tumors are the second most common cancers of childhood. They may occur at any age, but are seen most often in children 5 to 10 years of age. Symptoms include seizures, morning headaches, vomiting, irritability, changes in eating or sleeping habits, increased tiredness, clumsiness, or behavior problems. Diagnosis is often hard because these symptoms can point to many other problems.

Diagnosis of a suspected brain tumor is through X-rays, CAT scans, or MRI of the head, and spinal fluid tests.

Treatment is often surgical removal of the tumor. In some cases radiation therapy is used after surgery. Chemotherapy is sometimes given to shrink tumors before surgery, or for tumors with a high chance of coming back.

Neuroblastoma.

Neuroblastoma is a tumor that comes from young nerve cells that grow abnormally. More than half of these tumors occur in the adrenal glands, which are found in the abdomen near the kidneys. This type of cancer is found only in children. All affected children show signs of the disease by age five.

Symptoms vary by tumor site(s). Stomach complaints such as pain, diarrhea, and loss of appetite are seen. Tumors may be found in the chest, head (around the eye), neck, or spinal column. Tumors in these sites may cause a cough, shortness of breath, bruising or drooping of an eyelid, facial flushing, or changes in motor skills.

Diagnosis is done through CAT scans, ultrasounds of the abdomen, biopsies, and a 24 hour urine collection.

Treatment of children with local disease may be through surgery alone, but most require a combination of radiation, chemotherapy, and surgery.

Wilm's.

Wilm's tumor is a cancer that begins from cells in the kidney. It occurs in children up to age 15, and is rare in older patients. The most common symptom is a swelling or a lump in the abdomen. Other symptoms include stomach pain, blood in the urine, fever, weight loss, decreased appetite, and tiredness.

Diagnosis begins with many tests. X-ray tests of the kidneys including CAT scans, ultrasounds, and special dye tests may be done. The diagnosis is confirmed by looking at the tumor after it is removed.

Treatment of choice is surgery, followed by radiation and/or chemotherapy.

Rhabdomyosarcoma.

Rhabdomyosarcoma is a type of tumor that starts from muscle cells. It often occurs in the muscle around the eyes, in the head, neck, pelvis, or in the arms or legs. It occurs slightly more often in males than females. It most often affects children age 2 to 6. Symptoms vary on the site of the tumor, but an obvious lump or swelling is present in most cases.

Diagnosis relies on biopsy. Sign of tumor spread is sought with X-rays, scans, bone marrow and spinal fluid tests.

Treatment is through surgical removal of the tumor, followed by intensive chemotherapy and radiation.

Osteogenic Sarcoma.

Osteogenic sarcoma is the most common type of bone cancer in children. The tumor usually grows in the ends of bones, most often around the knee and the shoulder. It occurs in persons between 15 and 25 years of age and more often in males than females. The first symptom is pain and swelling over the area of the tumor. As the tumor grows, it pushes on the muscles, blood vessels, and nerve endings causing more pain, swelling, and weakness.

Diagnosis can be hard because the disease is easily confused with local infection, injury, arthritis, and non-cancerous tumors. Although osteogenic sarcoma may be suspected by the way the bone looks on an X-ray, only biopsy can confirm the diagnosis. This disease commonly spreads to other parts of the body, like the lungs. Chest X-rays, CAT scans, and bone scans may be done to look for spread before starting treatment.

Treatment often involves amputation (cutting off) of the limb. Sometimes limb saving treatment may be an option. Surgery is followed by chemotherapy. An artificial limb and physical therapy are important parts of care if the limb is lost.

Ewings Sarcoma.

Ewings sarcoma is a bone cancer that affects the bone shaft. It may be found in any bone in the body, but not often in the long bones. It usually occurs in persons 10 to 25, is seen more often in males than females, and spreads to other bones and the lungs. Symptoms include pain and tissue swelling. More general symptoms including fever, chills and weakness also are seen.

Diagnosis depends on biopsy reports. Bone scans, X-rays of bones, chest, and liver scans may be done to look for spread of the cancer.

Treatment is primarily through radiation and chemotherapy. Surgery is an option if the bone involved is one that can be done without, such as a rib.

Retinoblastoma.

Retinoblastoma is a rare cancer of the eye. It may be hereditary, and one-third of the cases may involve both eyes. The tumor may be noticed at certain angles as a white "cats-eye" reflex. As the tumor grows, the eye may redden and become swollen.

Diagnosis of this type of tumor needs a thorough interior eye exam. This cancer tends to stay localized for long periods of time, but it can spread to other parts of the body.

Treatment goals are to save vision by killing the tumor with radiation therapy. If the tumor is so large that there is no hope of saving the vision, the eye is removed. Radiation and chemotherapy may be used to treat cancer that has spread to other parts of the body.

DIAGNOSTIC TESTS

Biopsy.

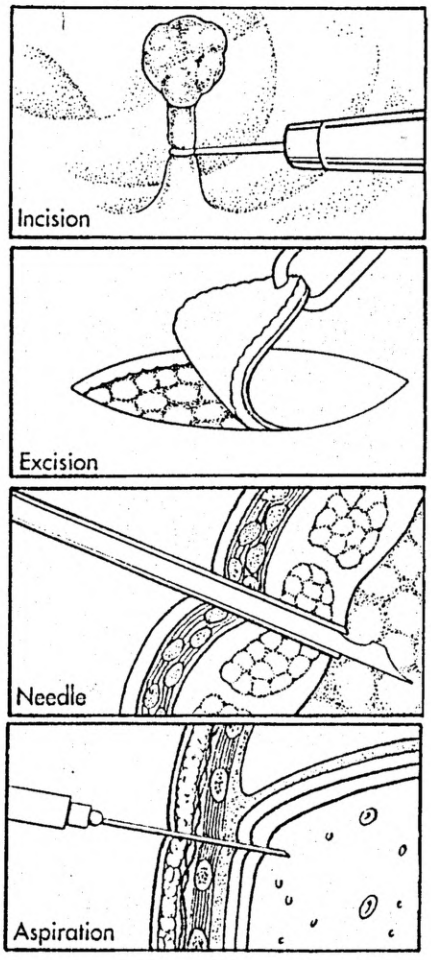
Biopsy is a procedure used to look at the tumor under a microscope to decide whether a tissue is cancerous or benign (not cancerous).

The three types of biopsy are:

1. *Incisional biopsy* is the removal of part of the tumor.

2. *Excisional biopsy* is the removal of the whole tumor.

3. *Needle/aspiration biopsy* is the removal of fluid or tissue through a needle.



Types of Biopsy
(From Cancer Nursing, 1992. A. Belcher, Ed. Mosby: St. Louis)

Blood Tests.

Blood tests look at the blood and its parts. There are many kinds of blood tests. The blood is obtained by taking blood from a vein or by a fingerstick. Some of the tests that may be done are:

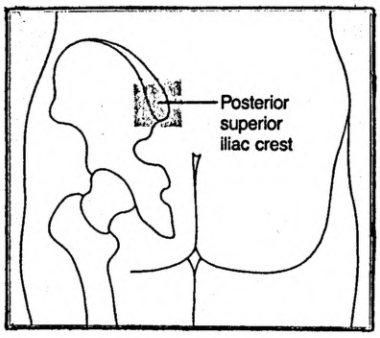
1. *White blood count* (WBC). The white cells, the parts of the blood that fight infection, are counted. This test is used to detect the presence of leukemia. A person taking chemotherapy often has a lower then normal WBC. The normal white blood cell count is between 5,000-10,000 per cubic millimeter of blood.
2. *Hemoglobin* (HBG). Hemoglobin is a substance in red blood cells that carries oxygen and gives blood its red color. Lower than normal amounts of hemoglobin indicates anemia. The normal hemoglobin varies with age and sex, but generally a level of 12 grams or more is acceptable.
3. *Hematocrit* (HCT). The word hematocrit means to "separate blood". The red blood cells are spun out and measured. Normal hematocrit varies according to age and sex, but generally a value of 30 or less indicates anemia.
4. *Platelet count.* The number of platelets, the part of the blood that helps stop bleeding, are counted. The normal counts are between 150,000-350,000. Low counts may indicate a problem with blood production in the bone marrow.

Bone Marrow Aspiration.

Bone marrow is removed from a large flat bone, usually the hip bone, through a large bore needle and examined in the laboratory. The test is used to diagnose leukemia, to check response to treatment, or to see if other cancers have spread to the bone marrow.

For the test, the chid lies on his or her stomach with a pillow under the hips. It is very important to hold still. The skin is cleaned with an iodine solution ("brown soap") to kill bacteria. Then the skin is numbed with a local anesthetic (xylocaine, lidocaine) and then a bone marrow needle is put through the skin into the spongy part of the bone. A feeling of pressure is noted. Once the needle is in place, marrow is pulled into a syringe and sent to the laboratory.

Usually there is only brief pain at the site, and activity may be resumed almost right away. Tylenol may help with the pain if it is bothersome.



Bone Marrow Aspiration
(From Cancer Nursing, 1992. A. Belcher, Ed. Mosby: St. Louis)

Lumbar Puncture.

Lumbar puncture (spinal tap or L.P.) is used to decide whether cancer cells or infection is present in the cerebral spinal fluid (CSF) that surrounds the brain and spinal cord. It is also used to deliver anticancer drugs directly to the brain and spinal cord.

This test is done with the child lying on one side or sitting. It is very important that the lower back is rounded to open the spaces between the back bones (vertebra). After positioning, the lower back is numbed, either by injecting xylocaine (lidocaine) or through the use of Emla cream (*see p. 67*). The child is held in a tight ball and the needle is inserted between the back bones into the fluid filled space just below the spinal cord. A sample of CSF is obtained and examined for blood and cancer cells, protein and sugar, and cultured to check for infection. Drugs may also be injected through this puncture site.

Most often there are no after effects, but sometimes a headache occurs when sitting or standing. The headache may be prevented by lying flat for about an hour after the test, and by drinking more liquids after the test. If drugs are given into the spinal fluid, nausea and vomiting may occur. Drugs to decrease nausea will be prescribed by your doctor if it occurs.

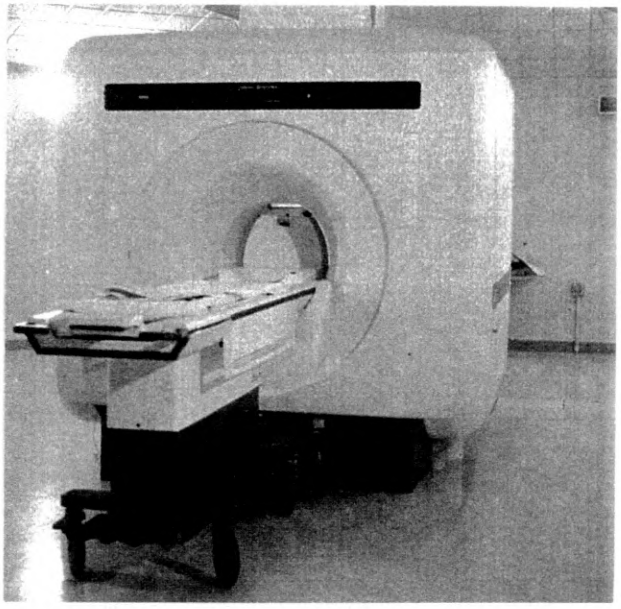
Computerized Axial Tomography.

Computerized axial tomography (CAT scan) is a X-ray technique for finding masses in the soft tissues of the body. While the child lies still, a narrow X-ray beam directed by a computer revolves around him or her. In a matter of seconds, the pictures appear as three-dimensional pictures on a TV screen. Lying still in a tube may be hard and scarry for the small child. Sedation ("sleeping medicine") may be used to make the test easier for the child and the staff.

Magnetic Resonance Imaging.

Magnetic resonance imaging (MRI) is like CAT scanning except it provides pictures based on the magnetism in the cells of the body and its interaction with radiowaves. A huge electromagnet is used to find hidden tumors by mapping the vibrations of the atoms of the body on a computer screen.

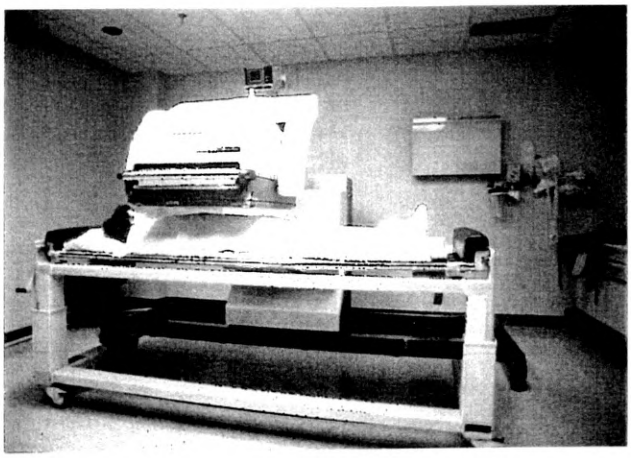




CAT Scan MRI
(From Cancer Nursing, 1992. A. Belcher, Ed. Mosby: St.Louis)

Scans.

Scans are used to find problems in the liver, brain, bones, kidneys, and other organs. In these tests, chemicals that collect in certain organs are "labeled" with a radioactive material. The child drinks the material, or it is injected into a vein. After a short waiting period, electronic devices track the radioactive material as it collects in the body. By looking at how the material is distributed in the body the doctor can see whether an organ is working right, or if it contains an abnormal mass. Your child will not be radioactive during or after the tests.



Bone Scan
(From Cancer Nursing, 1992. A. Belcher, Ed. Mosby: St.Louis)

Ultrasound Studies.

Ultrasound studies use sound waves above the range of human hearing to create "echoes". The echoes are electronically changed into images. The sound waves bounce off of tissues differentl. Tumors create echoes that are not like those from regular tissue. It is very accurate in telling cysts from solid masses, but cannot alone distinguish between cancerous and non-cancerous solid tumors.

TREATMENT

Treatment.

When your child is diagnosed with cancer, it is best to begin treatment at a center that is experienced and has the resources to apply the most effective form(s) of treatment from the start. Your doctor can help you decide on which center is best for your child and family.

Once you have arrived at the center, your child will go through testing to confirm the diagnosis. Treatment will then be based on the type of cancer and how advanced it is. For many types of cancer, treatment programs are well planned out; however, research is constantly underway, and your child may be treated under a new or research plan (protocol).

It is important to remember that each child's response to treatment is different, so plans may need to be changed to allow for these individual differences. The treatment plan may look complicated at first, but each step will be carefully explained, and you will soon become familiar with the routine. It may be helpful to have a notebook to keep track of events, treatment changes, lab tests, and questions you may have.

In addition to the doctors at the treatment center, your child's usual doctor at home will continue to play an active role in his or her care. This is especially true when distance between your home and the treatment center is a factor. Your child's doctor and local hospital may do routine blood tests and give chemotherapy treatments, thus reducing the number of visits to the center.

The exact type of treatment depends on the type of cancer. Most patients receive surgery, chemotherapy, radiation, or a combination of these. Treatments aim to bring about a remission. Remission means the decrease or disappearance of the cancer. The first part of treatment is known as "remission induction". This is done through any of the three types of treatment. The second part of treatment, "remission maintenance", is aimed at reaching undetectable cancer cells that often remain in the body.

Surgery.

For many solid tumors, surgical removal is the first and most effective treatment. If the tumor is very large, radiation or chemotherapy may be used before surgery to decrease its size, make surgery safer for the patient, and lessen possible physical or functional defects.

Chemotherapy.

Chemotherapy is the use of anticancer drugs. These drugs may be taken by mouth (pills or liquids), given by injection (shots into the muscle or just below the skin), or by vein (intravenously or IV). Another method of giving anticancer drugs is by injecting it into the spinal fluid (intrathecally or IT).

Injections and IV insertions ("pokes") can be painful, so Emla cream *(see p. 67)* can be used to help decrease the pain which in turn helps to decrease the fear that many children experience. The use of venous access devices also alleviates the need for IV pokes for each treatment *(see p. 65-66)*.

Once your child's treatment plan is set up, you will learn about each drug and its side effects. You will also learn how to deal with these side effects and know what works for your child and what does not.

Radiation Therapy.

Radiation therapy is treatment by high-energy X-rays. The basic idea of radiation is simple: ionizing radiation (X-rays, radium, etc.) are used to kill cancer cells. The result is a decrease of the tumor's size.

There is no pain during treatment. It is a lot like having a plain X-ray taken, except the child needs to hold still a few minutes longer. Sometimes younger children need sedation ("sleeping medicine") in order to be able to hold still for the treatment. You will not be allowed in the room during the treatment, because this would expose you to unnecessary X-rays.

A doctor specializing in radiation therapy will talk to you before the treatments begin and explain the specifics about your child's treatment. He or she will also talk to you about the side effects of radiation therapy and how to deal with them if any should occur.

VENOUS ACCESS DEVICES

Venous Access Devices.

Venous access devices allow instant access to the bloodstream. They are tubes (catheters) that enter the body near the heart that are placed by a surgeon under anesthesia. There are two basic types of tubes:

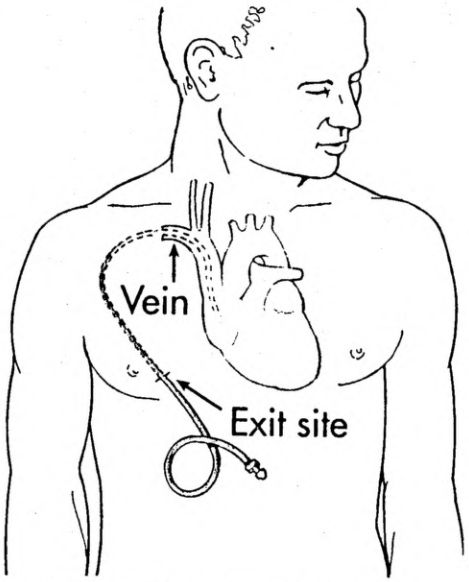
1. External central venous catheters (Hickman, Broviac, and Groshong catheters).
2. Implanted vascular access devices (Port-A-Cath, and Infuse-A-Port, etc.).

The doctors and nurses at the cancer center will help you decide what type of tube will be best for you and your child.

External Venous Catheter.

Central venous catheters allow the child to receive fluid, drugs, and blood over and over without the pain of a needle stick. Another plus is that blood tests can be taken from the tube as needed without a needle stick. This type of device is easy to use and may be left in place for months.

Parents must learn to change the dressing that covers the tube, change the cap, and flush the tube. These are not hard tasks to learn. Children often learn to help do some of the care themselves.

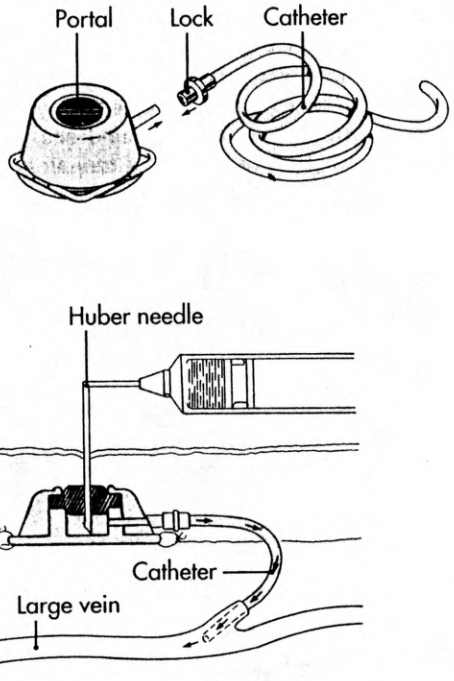


External Venous Catheter
(From Cancer Nursing, A. Belcher, Ed. Mosby: St. Louis)

Implanted Venous Access Device.

Implanted vascular access devices, or "ports", are like other tubes except the entire device is implanted under the skin. To get blood, or give fluids, drugs, or blood, a needle is inserted through the skin into the implanted chamber. The advantage to this type of tube is that it requires little care, and it is often cosmetically preferable.

When this device is chosen for a child, Emla cream (*see p. 67*) may be used over the port site to numb the "poke" area to make the needle insertion essentially pain-free, with the exception of the feeling of pressure as the needle is pushed through the port.



Implanted Vascular Access Device
(From Cancer Nursing, A. Belcher, Ed. Mosby: St. Louis)

Emla Cream.

Emla is a local anesthetic cream, a "numbing medicine". It works very well when needles are given in the tissue just under the skin. It is put on the skin before the "poke" to numb or "freeze" the area so the needle is not felt. This is helpful for procedures such as injections, IV or blood test pokes, or even a spinal tap.

Emla is applied in a blob on the spot where the needle will go in, *at least one hour ahead of time*. It should not be rubbed in. It should be covered with a piece of plastic wrap and taped gently down. This helps the drug go deeper into the skin and prevents the cream from getting rubbed off.

Words Used When Talking About Cancer.

Acute: Occurring suddenly over a short period of time.

Adjuvant Chemotherapy: The use of anticancer drugs after surgery in those whose cancer is most likely to recur.

Alopecia: Hair loss.

Ambulatory: The ability to walk.

Analgesic: A drug used to reduce pain.

Anemia: A condition in which there is a decrease in the number of red blood cells.

Anesthetic: Drugs that cause a complete or partial loss of sensation.

Anorexia: The lack of desire for food.

Antibody: A protein that acts against bacteria and other harmful material.

Antiemetic: Drugs that help control nausea or vomiting.

Artery: Blood vessels that carry oxygen rich blood from the heart to the body tissues.

Benign Tumor: A non-cancerous growth that does not spread to other parts of the body.

Biopsy: The removal and examination of tissue for diagnosis.

Blast Cell: An immature stage of cell growth.

Bone Marrow: The spongy material that fills the center of bones. It produces many parts of the blood.

Cancer: A general term for diseases characterized by abnormal and uncontrolled cell growth.

Carcinogen: A chemical or other agent that causes cancer.

Catheter: A hollow tube that is inserted into a body cavity.

CAT Scan (computerized axial tomography): A X-ray test that uses a computer to give a three-dimensional picture.

CBC (complete blood count): A series of tests to look at the parts of the blood.

Chemotherapy: Treatment with anticancer drugs.

Chronic: A word used to describe a disease of long duration or one that is progressing slowly.

Central Nervous System (CNS): The brain and the spinal cord.

Combination Chemotherapy: The use of two or more anticancer drugs for treatment.

Convulsion: Violent contraction and spasm of muscles over which a person has no control (seizure).

Culture: A laboratory test in which germs contained in body secretions are grown to determine the cause of an infection.

Cyst: A fluid filled sac of tissue. May be cancerous or non-cancerous.

Dehydration: Excessive loss of fluids from the body.

Diagnosis: Process by which a disease is identified.

DNA (deoxyribonucleic acid): The basic material of life. Chainlike chemical in the center of all cells that contains one's genetic code.

Electrolyes: A general term for the many minerals in the cell environment.

Emesis: To vomit.

Erythrocytes: Red blood cells.

Excision: Surgical removal of tissue.

Extravasation: Leaking of a drug out of the vein and into the skin.

Febrile: Fever.

Gastrointestinal: Pertaining to the digestive tract. Includes the mouth, throat, esophagus, stomach, small and large intestines, and the rectum.

Hematologist: A doctor who specializes in the study of blood diseases.

Hematology: The study of blood and blood forming organs.

Hematuria: Blood in the urine.

Hemorrhage: A general term for loss of blood.

Hyperalimentation: Intravenous nutrition, bypassing the gastrointestinal tract.

Immune System: The body's system of defenses against disease. Composed of white blood cells and antibodies.

Immunology: The study of the body's natural defenses against disease.

Infection: The invasion and growth of disease producing germs in the body.

Informed consent: The permission given by a person before any treatment. The patient, parent or guardian must understand the possible risks and benefits of the treatment and legally agree to accept those risks.

Intrathecal (IT): Within the spinal column.

Intramuscular (IM): The injection of a drug into muscle tissue, where it is absorbed.

Intravenously (IV): The administration of a drug into a vein.

Jaundice: Yellowish color of the skin and white portion of the eyes due to the accumulation of bilirubin, product of the breakdown of hemoglobin.

Leukemia: A cancer seen as the uncontrolled growth of white blood cells.

Leukocytes: White blood cells.

Lumbar puncture (LP): A test that involves taking a sample of spinal fluid.

Lymph: A colorless fluid that bathes body cells and moves through the lymphatic vessels.

Lymph nodes: Bean shaped structures scattered along the vessels of the lymphatic system that act like filters, catching bacteria or cancer cells.

Lymphatic System: Circulatory network of vessels that carry lymph, and the lymphoid organs such as the lymph nodes, spleen, and thymus.

Lymphoma: A tumor of the lymphatic system.

Malignant: A cancerous tumor, likely to invade and destroy active tissue.

Metastases: The transfer of cancer cells from one part of the body to another.

Monocyte: One type of white blood cell that destroys invading bacteria.

Mucous Membrane: Lining of the internal surface of the body that produces mucous.

Neoplasm: An abnormal growth or tumor.

Oncologist: A doctor that specializes in cancer.

Oncology: The study of cancerous tumors.

Pathologist: A doctor that looks at and diagnoses the changes in tissue.

Plasma: The liquid portion of the blood.

Platelet: A type of blood cell that helps the blood to clot.

Prognosis: An estimate of the outcome of a disease; a prediction.

Prosthesis: An artificial limb.

Protocol: The outline or plan for a treatment program.

Rad: A unit of measure of radiation.

Radiation Therapy: The use of high-energy radiation to treat disease.

Radiologist: A doctor that reads and diagnoses X-rays.

Red Blood Cells: Cells that carry oxygen from the lungs throughout the body.

Relapse: The reappearance of an illness after treatment.

Remission: The decrease or disappearance of disease.

Sarcoma: A cancer of connective tissue such as bone, cartilage, fat, or muscle.

Sedative: A drug given to cause sleep or drowsiness; "sleeping medicine".

Tumor: Any abnormal growth in a localized area.

Vein: Blood vessels that carry blood towards the heart.

Evaluation

1. Did you find the information you were given helpful during the first days at the treatment center? Please give examples.

2. What other information might have been helpful to you during your initial hospitalization?

3. Did you find the materials you were given easy to read and understand? Please give examples of why or why not.

4. What suggestions or information would you give other parents who are going through the initial diagnosis of their child?

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Appendix B

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