

SOCIAL SUPPORT IN PEDIATRIC ONCOLOGY

By

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ABSTRACT

Having a child diagnosed with cancer creates turmoil and stress for all members of the family. Social support from family, friends, and professionals helps these families adapt to these new life events. Research has shown the importance of relationships with other people that have also experienced the same stressors. Utilizing the nursing process the social support needs of local families of children with cancer were assessed. Data were collected by telephone interview. Analysis of the information supported the development of two interventions which were the preparation of a printed parent support network and the organization and implementation of an informal gathering for socialization and support. The informal social gathering was evaluated at its conclusion and a tool was developed to evaluate the parent support network.

CHAPTER 1

INTRODUCTION

The diagnosis of cancer in a child is an overwhelming, emotional crisis event. Each family reacts to this horrifying news in a different way. The entire family unit is the focus of concern when a child has cancer (Williams, 1988). The crisis of having a child diagnosed with a life threatening disease is the beginning of a long period of stress and coping that involves medical treatment, its side effects, the uncertainty of the child's prognosis, and years of disruption for the family. Financial hardships, marital stress, alteration of routines, and role changes all occur during this time of stress and adaptation (Moore, Kramer, & Perin, 1986).

In this time of limited resources and increased patient loads, the majority of the care that nurses in the in-patient setting are able to provide is focused on the physical needs of the child with cancer. However, these families also have a significant need for emotional support, guidance, and education. The realm of pediatric nursing not only includes providing physical care to the child, but also includes the provision of holistic care to the families that

includes emotional support, education, and referral to appropriate local resources.

Research has shown that the amount of social support available greatly influences a family's coping abilities (Anderson & Shaw, 1994; Johnson & Lane, 1993; Lynam, 1987; Monaco, 1988; Yoak, Chesney, & Schwartz, 1985). Support is found in relationships with spouses, family members, and close friends. Support can also be obtained from health care professionals, religious organizations, and from mutual or self-help groups. Emotional support provided by people experiencing the same stresses, as the latter group, has been seen as very beneficial (Lynam, 1987). Often these groups or networks are formed to provide support to people experiencing a similar life event.

Children who are diagnosed with cancer in a rural community are transferred out-of-state to tertiary treatment centers to begin their treatment protocols. When these families arrive at the tertiary treatment center, they are met by a multidisciplinary team. The team includes physicians to handle the medical care and social workers to assist families with emotional issues and to help identify healthy coping strategies. Parent-to-parent support can be obtained in an informal setting such as the hospital unit when the children are hospitalized, or in a formal structure such as a parent support group or network specifically designed for pediatric oncology families (Brown, 1989). In larger metropolitan areas there are established support

groups, respite care agencies, and an abundance of other resources available when the family returns home.

Living in a rural state such as Montana creates obstacles for families that nursing professionals can help overcome. At the community hospital in Helena, Montana, not unlike other rural hospitals, the times when more than one child with cancer is hospitalized on a specific day is a rare event. This does not allow for parents experiencing similar events to meet and develop relationships. In small rural areas families return to little or no formal support system.

Professional nurses know that:

Individuals are not immune to the effects of problems experienced by other family members, nor do they generally resolve these issues independently. As a result all family members are a focus of concern when a child has cancer. How the family responds, and to what degree the family is able to successfully integrate the experience into their lives, may be a function of the adequacy of the family's social network system as well as their perception of available social support (Williams, 1988, p. 6).

Pediatric nurses who are current in their knowledge and comfortable with their abilities to assist families in times of crisis can have an enormous impact on the family's ability to cope with cancer as a part of their lives. Those caring for families experiencing childhood cancer are in an ideal position to assess the availability and adequacy of the family's social networks.

Standards relating to registered nurses' responsibility in applying the nursing process to clients are outlined in

the Montana Statutes and Rules Relating to Nursing (1995). These standards give nurses direction in the use of nursing assessments, developing plans of care, establishing interventions, and evaluating clients' responses to the interventions. Through the use of these standards as a framework, nurses can gain a better understanding of social support needs as well as coping strategies used by the families for which they provide care. Having an understanding of the rural families' experiences, nursing's plan of care and interventions become more relevant in meeting the specific needs of the patient's family.

Goals

The problem identified by this author is the lack of local support resources for rural families of children with cancer. In a rural area, such as Helena, Montana, that has few resources and few families experiencing cancer at any given time, a formal support network is required to connect the individuals in need.

The goal of this project was to initiate a support network for local pediatric oncology families that was based on assessment of the families' social support needs. Assessment of the family's social support needs was accomplished by a telephone interview. Questions were asked about their social support needs and how they felt these needs could be met. Determined from the assessment findings,

possible options were identified to assist them in meeting their social support needs. These options included: providing a comprehensive list of local, regional, and national resources; organizing a parent telephone support network; facilitating an informal gathering to allow families to meet; and the formation of a parent support group. This project focused on facilitating an informal gathering of the families and on the development of a written telephone support network.

Evaluation of the interventions was accomplished by interviewing the families after they met at an informal gathering and received written information in the form of a telephone support network and resource guide. Follow up evaluation was also done using a brief written evaluation tool one month after the informal gathering.

CHAPTER 2

REVIEW OF LITERATURE

The review of the literature focuses on the concepts of stress and adaptation as they relate to families with cancer and the utilization of social support in coping with a child with cancer. The framework of the nursing process is used as the guiding structure for delivery of nursing care to these families. Assessment of the family's reaction to the stress caused by this crisis event and the identification of social support needs allows for the development of a plan of care and interventions that support coping with this diagnosis.

Crisis and Stress

Crisis is not the problem, but occurs as a response to the problem. Crisis is defined as a perceived insolvable problem brought on by stressful events, causing a loss of equilibrium in the individual (Hockenberry & Coody, 1986). Crisis is a self-limiting phenomenon that lasts about 8 weeks. The time of crisis may last longer if the system has more than one crisis superimposed on another. The Chinese define crisis as both danger and opportunity. Crisis is a danger because it threatens to overwhelm the family and may

result in psychological problems. It is also a time for opportunity because during times of crisis individuals are more receptive to therapeutic influences (Aguilera & Messick, 1982). It is during this time that the influences and support of others are beneficial to those in need. A crisis results when a family's resources and past adaptive strategies are not adequate to handle this type of threatening situation. Therefore, a family crisis refers to a disruptive state in a family's life when an extremely stressful event or series of events significantly impacts the family's resources and coping abilities with no resolution to the problem in the near future (Friedman, 1992).

There are two types of crisis that families may undergo, developmental or situational. Developmental crises arise from stressors that families experience in the process of psychological growth of its members. Situational crises are events and stressors that are not expected or common in life, such as the death of a loved one (Friedman, 1992; Leahey & Wright, 1987).

Crisis theory describes three phases of response. The first phase is the precrisis phase where the individual tries to maintain equilibrium by adapting to physical and psychosocial changes within the context of normal life events. The second phase is the crisis phase which is a time of disorganization and attempts are made to solve the problem. These attempts may be successful, or may fail to

alleviate the problem, at this point one may seek additional resources that will assist in developing new responses to the problem. In the postcrisis phase, successful problem resolution reduces the crisis and provides growth of a new strategy for the individual's future adaptation processes (Otto, 1991).

A family in crisis is characterized by instability and disorganization. This is certainly true with the family system of a child with cancer. In some family systems, there may not be a period of time that a crisis or potential for a crisis does not exist (McCorkle & Hongladarom, 1986).

Hockenberry and Coody (1986) identify specific times in the course of living with cancer that crisis points occur. The initial phase of distress occurs at the time of diagnosis and is one that cannot be resolved by ordinary coping strategies. Feelings of fear, anxiety, disbelief, and helplessness emerge. The family's previous experience with cancer or serious illness influence their reaction to the news. Individuals tend to rely on their own past experiences to assist them in reacting to each new crisis.

The time of receiving treatment is also stressful. Treatments vary in frequency and intensity depending on the type of cancer. Families may be required to leave familiar surroundings to receive treatment causing separation from support persons. Cost of treatment adds additional stress on families. The actual treatment regime may cause the child to feel ill and require more of the parent's time and energy.

Risks associated with treatment protocols are a cause of alarm for parents. There is much for the parents to learn in regard to providing personal care to their child where once they were the experts about their child's needs. Control over their child's life and health now rests with strangers and this also increases stress.

Discontinuation of therapy causes yet another crisis as the family again enters a new situation. Families have gradually adjusted to their new routines and become comfortable with an altered way of life. Frequent contact with the medical professionals is reassuring to them. New friendships may have been formed, and a large portion of the family's support may have been obtained from these relationships. The treatment itself becomes a comfort to them when there has been no sign of the disease during the treatment phase. Ceasing the treatment brings the fear that the cancer will return. Preparation for separation from treatment should begin months before the end of therapy. Parents need time to adjust to this change.

The final two crisis points identified are the diagnosis of a relapse and a change in prognosis or end stage disease. Although parents are faced with the prospect of death at the time of diagnosis, hope for the future and positive response to treatment pushes those thoughts to the background if only for a short time. Parents are then faced with the reality that all that can be done has been done and the focus changes from "how can we treat the disease" to

"how can we make it easy for the child" (Hockenberry & Coody, 1986, p.446).

Hill's Family Stress Theory

Hill's Theory of Family Stress describes the factors that produce crisis or noncrisis in families (Friedman, 1992), and accounts for the existence of variation in families reacting to the same stressor (Nugent, Hughes, Ball, & Davis, 1992). The theory was first published in 1949, based on research conducted on war-induced separation and reunions. The theory entitled ABCX, identified a major set of variables and their relationships that led to family crisis. The framework has two parts. The first part deals with the determinants of family crisis:

A (the event and related hardships) interacting with B (the family's crisis meeting resources) interacting with C (the definition that the family makes of the event) produces X (the crisis). (Hill, 1965, p. 36, as cited in Friedman, 1992)

The three basic factors involved in Hill's theory are described as follows. Factor A is the actual presence of the stressors or stress-events. The second factor, factor B, is the family's resources and use of coping mechanisms that are used to influence the outcome of crisis or noncrisis. In this process the family makes use of their previous coping resources that have developed from previous life experiences. The final factor, factor C, is the family's perception and interpretation of the stressors or stressor-

event. The result of this process is factor X. Factor X is the end result, crisis or noncrisis. Two dimensions, family resources and perception of the event, can be altered changing the end result.

Interventions with families in these areas are beneficial and decrease or alleviate a crisis state. Providing social support where families can share with others that have faced similar events is one example of an intervention that may change the family's perception of the stressors and expose them to new coping responses. For the purpose of this project crisis and stress are defined as the cognitive, emotional, biological, spiritual, and social responses of a family unit to the diagnosis of a child that has cancer. This wholistic response is based on the family's resources, coping mechanisms, and their perception of the event.

Coping

Coping is defined as constantly changing cognitive and behavioral efforts to manage internal or external demands that are appraised as taxing or exceeding the resources of the person (Lazarus, 1991). Coping is the interactional process between the person and the environment that allows the individual to move from the experience of a life stress to adaptation. The goal of coping is problem resolution (Otto, 1991). Family coping differs from that of individuals

in that multiple persons at various developmental levels are participating in the coping process (Birenbaum, 1991).

Parents' coping abilities vary with the diagnosis of the child, the intensity of the treatment protocol and the prospects of survival. Oakhill (1988) identified coping tasks for parents specific to each stage of illness. The task at the time of diagnosis is for the parents to accept the reality of the diagnosis, to express feelings of grief and sadness and to be able to communicate these feelings with friends and family members. During remission, the task is to utilize adaptive denial in order to suppress anxiety and allow the child to reenter the family and social life.

For the family whose child remains in remission, the task is to begin separation from the medical community. The family must loosen the ties with the hospital and activate relationships and activities in the outside community. In times of relapse, or the terminal stage of illness, the family must begin the process of anticipatory mourning and loosening of the relationship bond with the child. This preparatory task allows for reorganization of family relationships after the loss of the child.

Family adaptation results from the use of coping strategies within the family and coping patterns within the community. These strategies are not created in a single instant, but are the results of learned responses from previous life events. Adaptation strategies may include, but are not limited to, the maintaining of satisfactory

communication and organization in the family, promoting independence and self-esteem in family members, maintaining family bonds, and the maintenance and development of social support for the family unit (McCubbin, Olson, & Larsen, 1987).

Identifying families' early coping reactions helps identify adaptive or maladaptive coping patterns that may persist over the course of the illness. Families that are rated as showing adaptive coping have significantly fewer problems and stresses during the illness. Those families that show maladaptive coping early on in the illness continue to suffer from family dysfunction (Oakhill, 1988). Continued denial that the child is ill is one type of maladaptive coping. The problem does not go away when not recognized. This may lead to non-compliance with treatment, or refusing treatment all together.

McCubbin and Patterson's Double ABCX Model

The creation of the Double ABCX Model by McCubbin and Patterson (1981) was accomplished by expanding on Hill's Family Stress Theory. The original theory addressed the precrisis state but did not include or describe the outcomes of the family efforts to adapt after the crisis. The Double ABCX Model focuses on three units of analysis: the individual family member, the family unit, and the

community. Each of these units have their own demands and capabilities.

Family adaptation is accomplished through reciprocal relationships where the demands of one are met by the capabilities of another. Adaptation is defined in this model on a continuum from bonadaptation (positive adaptation) to maladaptation (negative adaptation) (McCubbin & Patterson, 1981).

The Double ABCX Model consists of three factors. Factor aA, refers to family demands and "the pile-up of family stressors" (McCubbin & Patterson, 1981) that is important in predicting family maladaptation. They explain that families do not experience one stressor at a time, rather they experience clustering of stressors from different directions at the same time, including prior family strains, ambiguity within the family, and the initial stressor.

The second factor identified is Factor bB, the family adaptive resources. Resources are the family's capabilities to meet the demands that the family incurs. This includes the family member's personal resources, the family system's internal resources, and the family's existing social support.

Factor cC is unchanged from the factor C in Hill's theory. This is the definition and meaning the family gives the stressor.

The adaptation stage, Factor xX, is represented as a continuum from maladaptation to bonadaptation. The addition

of the postcrisis response to this model allows for a complete understanding of the cause, effects, and results from stressors on the family. The identification of a family's level of adaptation gives direction when planning interventions and evaluating the family's response. For the purpose of this project coping and adaptation is the process that a family with a child having cancer must undergo that enables them to endure this time in their lives.

Social Support

Social support has been defined in numerous ways by researchers. These definitions are sometimes based on the operationalization of the term. For example, the quantity of the connections (number of friends), quality (having people you can trust), utilization (spending time with people), meaning (the importance of friends), availability (having someone available when needed), and satisfaction with one's support (Brownell & Shumaker, 1984).

During the last century, the effects of relationships between people have been examined closely. One area that has been examined is the relationship between people's emotional and psychological well-being, and the amount of interaction they have with other people. In 1897 Durkheim, a sociologist looked at the relationship between the loss of social integration and suicide. He found that the suicide rates were higher in people with few social ties and felt the loss

of social integration, or "anomie", was antithetical to psychological well-being (Brownell & Shumaker, 1984).

In 1974, John Cassel, a physician epidemiologist, addressed the importance of interpersonal relationships and the promotion of health. He hypothesized that breaks in social ties that occur under stressful conditions increase one's susceptibility to illness. Cassel (1974) then proposed that group support would protect, or buffer, individuals from the harmful physiological and psychological effects of such conditions, and suggests that it would be easier to protect health through the mobilization of social support than through the reduction of exposure to environmental stressors.

Building on Cassel's foundation, Gerald Caplan (as cited in Brownell & Shumaker, 1984), a social psychiatrist, characterized social support as consisting of individuals who help others mobilize their psychological resources in order to deal with emotional problems. They assist people with tasks and provide others with money, materials, information, and advice to help them deal with a particular stressful situation.

Social support may also be described as a concept or a cluster of interrelated social factors. The concept, social support, is described as the beneficial effects of social relationships that enhance health and well-being. Viewing social support as a cluster of social factors implies that the more close friends, greater involvement in

organizations, and close family ties a person has, the more likely the person is to be healthy and happy (Bruhn & Phillips, 1984).

Cobb (1976) looked at social support from a different perspective than Cassel and Caplan. He saw social support as a moderator of life stresses, a buffer system that is used in situations of crisis rather than to produce a dramatic improvement in adaptation. In his conceptualization of social support as "information" three types are identified. The first is emotional support or information that shows one is cared about or loved. Esteem support, the second type, leads the individual to believe that he or she is valued or esteemed. Social integration is the last class identified and is information that one belongs to a network of communication and mutual obligation (Dimond & Jones, 1983). Cobb's interest in social support came from findings in clinical medicine, and he hypothesized that social support provided protection from pathological states, enhanced recovery from illness, and increased compliance to medical regimes (Sarason, Sarason, & Pierce, 1990).

Three major factors that help classify when different types of support will be the most beneficial in a certain circumstance are as follows: the nature of the situation, the time when support is provided, and the resources of the individual (Dimond & Jones, 1983). What may be perceived as effective support in one instance may not work in another situation. A thorough evaluation of the situation must be

done to allow individuals to benefit from the support offered.

Weiss (1974) organizes social support into four definitional categories. These are support defined as relational provisions, support as information, support as structure, and support as interaction (Dimond & Jones, 1983).

Relational Provisions

Four types of support as relational provisions are defined as they relate to relationships outside of the immediate family. The first is attachment, or a sense of security and place. A lack of attachment results in feelings of isolation and loneliness.

Social integration is the second type and is described as the less intimate sharing usually found in the group setting, again social isolation may result from the lack of integration. The third is feeling competent in a social role. This may be provided by work, friends, and family relationships and gives a reassurance of worth. Lack of reassurance may result in a sense of uselessness.

The final type identified by Weiss is obtaining guidance or the access to a trustworthy authority figure who can provide assistance. This type of support is found in relationships with professional persons during times of acute stress or crisis. Hopelessness may occur without this guidance.

Information

The second category of support identified is support as information. Three classes of information are mentioned. The first class is information that shows one is cared for and loved, termed emotional support. The second class is information that shows value and esteem, labeled esteem support. The final class is information that shows membership in a network of communication and mutual affiliation (Dimond & Jones, 1983).

Structure

Support as structure is the third definitional category. This category looks at the structure of the social network in terms of size, density, homogeneity of the members, and the dispersion of membership. Size of the network looks at the number of people that the individual maintains social contact with or those that may be contacted in a time of increased need. The density of the network addresses the extent that the individual members of the network contact one another separate from interactions that include the individual of concern. Homogeneity of membership is concerned with the extent of similarities of members in the network. Similarities in age, sex, social class, attitudes, and lifestyles are evaluated.

The final characteristic of the third definitional category is that of dispersion of membership. This addresses the ease of making face to face contact between the members

of the network. These properties of an individual's social network provide information in evaluating the extent of accessibility and availability for social interaction.

Interaction

The fourth definitional category, support as interaction, is summarized into three dimensions by Mitchell they are content, directedness, and intensity (as cited by Dimond & Jones, 1983). Content describes the meaning that individuals give to their relationships. Directedness is the amount of mutual sharing that occurs. Intensity is the strength of the relationship between two people and their willingness to carry out obligations in the relationship against opposition. The extent of adequate and appropriate support that people receive in times of need is largely determined by the structure and interactional properties of their support network (Dimond & Jones, 1983).

Shumaker and Brownell (1984) define social support as "an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (p. 11). They consider the costs and benefits of the supportive exchange for both participants. The possibility that there may be an incongruence between the perceptions of the person offering support, and that of the recipient of the support is discussed. They also differentiate between health-compensating and health-sustaining functions of support.

The concept of reciprocity is used in Shumaker and Brownell's (1984) definition of support and implies that people generally return the benefits they receive from others. One example of how this works is in the process seen in formal support groups where mutual sharing and caregiving occurs. When talking about reciprocity a difference is identified when the relationship is with a formal support provider (medical professional, clergy) versus an informal support person (family, friend). Formal support providers do not require reciprocity in the same manner that is required by informal providers. Formal providers are less likely to feel threatened by the needs of the recipient due to role perception and definition. Formal providers are also able to provide more expert information as a form of support (Shumaker & Brownell, 1984).

Festinger's Social Comparison Theory

Festinger's Social Comparison Theory, developed from studies in the early 1900's, suggested that social environment is an important factor in determining self development and one's behaviors. Festinger's original work focused on two areas of research. The first studied how individuals set goals or levels of aspiration, and the second focused on the dynamics of social communication (Suls & Miller, 1977).

Festinger found that when standards of comparison (group norms) are available and when individuals found that they performed comparable to the reference group, they showed a greater stability in evaluating their abilities. It was also discovered that subjects lowered their aspirations if they performed at a higher level than the group norms. Inversely, they raised their aspirations if they performed at a lower level. The second focus of research was the observation of the variety and direction of interpersonal communication. Festinger concluded as the result of these prior research topics that interpersonal information and uniformity are powerful determinants of behavior.

The Social Comparison Theory emphasizes how individuals use groups (reference groups) to fulfill their informational needs to evaluate their opinions and abilities. The theory stipulated that people first attempt to evaluate their opinions or abilities through objective nonsocial means, yet if these means are not available they evaluate themselves through comparisons with the opinions or abilities of other people (Suls & Miller, 1977).

Festinger (1954) stated comparisons must be made between people that are similar; if the group is too divergent, an adequate evaluation is not possible. Individuals who favorably compare themselves with others may gain benefits that include increased self confidence, and reduction of stress produced by challenging situations, thus buffering the effects of stressful events. Relationships

with people that are currently or have previously undergone the same stressful life event creates a beneficial means by which individuals can analyze their own coping abilities (as cited by Suls & Miller, 1977).

Social support can be classified operationally, as a concept or cluster of defining characteristics, by definitional categories and as an exchange process. Thus the primary theme identified is that of social support being based on relationships between individuals. These relationships are important to the maintenance of one's emotional and physical well-being and adaptation to crisis and stress.

Research has demonstrated that individuals benefit during times of increased stress from interactions with others. Social support is seen as being a part of a group that supports the exchange of information, sharing of experiences and reinforcing the belief that there are others that will come to the aid of the individual during times of need. Mutual satisfaction and the continuance of supportive interactions relates to Festinger's Social Comparison Theory.

Conceptual Framework

The nursing process is the framework used for this project. Professional nurses use systematic observational and problem-solving techniques to identify client or family

needs. The foundation for all patient-nurse interactions is the nursing process. The five components of the nursing process are assessment, diagnosis, planning, implementation, and evaluation. Each step in the process depends on the accuracy and completeness of the preceding step.

Individualized plans are necessary for each client or group of clients, as each individual interacts in a unique way with the environment and must be assessed within the context of his uniqueness (Carpenito, 1992).

Assessment is the first phase of the nursing process. It is a systematic collection of data that determines the client's health status, functional status, and evaluates present and past coping patterns. Data are obtained from interviews, physical examinations, client observation, review of previous records, and through collaboration with other providers. From the holistic view it is important not only to gather information about the client's physical needs; but spiritual, developmental, sociocultural, and psychologic needs must also be assessed. Accurate assessments result when effective communication, systematic observation, and accurate data interpretation skills are used by the nurse.

Diagnosis is the next step in the nursing process. Nurses use complex thought processes, scientific theory, and information they have previously used to assist with the interpretation of the data. Conclusions are then identified

as either a collaborative problem, an identified nursing diagnosis, or at high risk/potential for a problem.

Planning follows the identification and assessment of client needs. The planning phase has three components: prioritizing the client needs, identifying outcome criteria and goals, and negotiating interventions with clients. Ranking the client's perceived needs lays the framework for prioritization of needs. This allows for a systematic approach to meeting these needs. The identification of outcome criteria and goals provides a way for measuring the client's progress and the nurse's performance.

Nursing interventions are developed and prescribed by nurses in meetings with the clients. These interventions may be used to reduce or eliminate factors that contribute to client needs (prevention), promote a higher level of wellness, or monitor status (maintenance) of the client.

Implementation of the nursing interventions is the component of the nursing process that involves the application of skills that are needed to assist the client in meeting their needs. The knowledge and skills of the nurse are the basis of the provision of care, teaching clients about their health, counseling clients about health decision making, and performing specific physical care. The outcome for the client is the resolution or reduction of health problems and assistance in the identification of risks and problems while exploring available resources.

Evaluation is the final component of the nursing process. The evaluation consists of evaluating the client's status, progress towards goals, and relevance of the current plan. This is done through an interactive process between the client and the nurse.

The nursing process is an interactive process that begins whenever a client and a nurse begin a relationship. The assessment phase is a continuous process of data collection that is done during each and every interaction between client and nurse. Evaluation of the plan leads to revisions and alterations that are needed to assist the client and nurse in reaching the goals. Client goals also change over time, and the priority of needs fluctuates with changes in health, environment, and perceived needs.

The identification of stressors, personal perceptions and beliefs is a necessary portion of the assessment phase in the nursing process. This comprehensive assessment is needed to provide the information on which all planning, interventions, and evaluation is based. The use of Hill's Stress Model, the Double ABCX model, and the nursing process provides guidance and allows for a systematic way of assessing needs and concerns, identifying how previous life events affect coping abilities, and gives direction to what type of interventions will help in the adaption process.

CHAPTER 3

METHODOLOGY

Project Design

The project focused on the development of a support network for pediatric oncology families in Helena, Montana. A literature review provided an increased knowledge and awareness of stress and coping experienced by families of children with cancer. The review of literature also examined social support and the benefits gained by families through sharing experiences with others who have or currently are living through the same life event.

Ten families were identified through the author's personal clinical experience in providing chemotherapy and nursing care to local children with cancer. The assessment process began with verbal telephone interviews of eight of the identified families that have children currently under treatment or have been treated for cancer in the last five years at St. Peter's Hospital in Helena, Montana. One family was not reached for an interview and one family re-entered the local area after the interviews were completed. The interviews consisted of four questions (Appendix A) followed by open discussions about their individual experiences.

Available local resources were assessed. This identified a lack of established social support for families of children with cancer.

Responses from the families follow. Eight families felt having access and talking to other families would be beneficial; two families identified needs that focused on support resources that offered financial help; three families thought a parent support group should be organized, but they were unable to commit to biweekly or monthly meetings due to other time commitments. Other suggestions, each given by one respondent, included having a social worker available in the hospital setting, making current information available in a resource library, and providing sibling support. These responses were analyzed and the primary theme identified was the need for a mechanism to allow access to and conversation with other parents in this community. This need was presented in the expressed wish to meet and talk with other parents that have previously experienced the common stressors associated with cancer in children. Two mothers also had previously had limited interaction with another parent and communicated a desire for increased interaction.

Interventions were developed using the analysis of the data from the telephone interviews, to provide a written telephone support network for families and to plan an informal gathering that would provide an opportunity for socialization of the family members. The evaluation of these

interventions began by direct observation of the interactions of the families at the gathering and will continue by obtaining written feedback from the families one month after the distribution of the telephone network at the social gathering.

CHAPTER 4

PROJECT OUTCOME

Results

Based on the responses from the telephone interviews a telephone support network was established. A form (Appendix B) was sent to nine families to gather information they wanted to share about their child and to obtain phone numbers and addresses of those that wanted to be included in the telephone support network. Consent was obtained from each of the seven families that returned their forms for inclusion in the telephone network (Appendix C). The families on the telephone support network agreed to be resources for other families needing to obtain information or emotional support.

A listing of local families, their phone numbers and addresses along with a brief description of their child's cancer experience was completed. This written telephone support network (Appendix D) was given to the local families currently involved with pediatric cancer and will be made available for future families that utilize the Pediatric Unit at St. Peter's Hospital in Helena, Montana, for cancer

treatment. For the purpose of this project to maintain the privacy of the persons interviewed, brief family profiles were included in the telephone support network without addresses or telephone numbers.

The wish to meet others with similar experiences was also identified. To facilitate this type of family interaction in the community a social gathering in the form of a pizza party (Appendix E) was organized and held on March 4, 1996. Nine families were invited and seven families attended. Those in attendance included families and extended family members for a total of twenty-seven people. The author introduced the families to each other upon arrival which facilitated their sharing of experiences. Many of the children played video games and visited leaving the parents free to talk with one another.

Initial evaluation of the project was done through observation of personal interactions and verbal feedback from the families at the informal gathering. Conversation between parents, children, and the author flowed freely. Parents shared their experiences and concerns with one another. The setting was non-threatening and conducive to informal non-pressured interactions. Families expressed their thanks for organizing the gathering and expressed their desire for future meetings with the other families. One family requested to use the written information the author had obtained on starting a parent support group. This communication validated that the planned interventions were

needed but also shows that socialization and personal interaction needs to continue between the families in the community. This process worked to allow the families access to one another in an informal setting.

Further evaluation of the family resource network will be conducted one month after the distribution of the telephone support network. Parents will be sent an evaluation tool and will be asked to complete it and return it to the author (Appendix F). The tool requests feedback on the presentation, and the effectiveness and helpfulness of the written data presented in the telephone support network. The feedback from the families will be used to evaluate the strengths and weaknesses of the telephone support network. The families' input will also be used to make changes to improve the effectiveness of the support network.

In the two weeks following the distribution of the telephone social network and the occurrence of the informal gathering, two episodes of informal feedback were received by the author. The first was a telephone call from a parent of a child recently diagnosed with cancer. This parent had obtained the author's phone number from a family that participated in the informal gathering and is part of the telephone support network. The family of the newly diagnosed child wants to be included in the network and is in need of information and emotional support.

The second episode of informal feedback with a parent who presently has a hospitalized child, reinforced the need

for continued social interaction for these families. This parent expressed a desire for continued interaction with the other families and asked if the hospital might in some way be able to help facilitate this. Her suggestion was to see if the hospital would allow for the use of a meeting room once a month for the families to gather.

Another possible option could be to ask the families to take turns in organizing an informal gathering, either meeting at their homes or in a public setting such as a park or restaurant, this would allow the meetings to remain informal in a less structured setting. From the data obtained and the feedback received since the informal gathering, it is apparent that the assessment of the local families' social support needs was accurate, and that the initiation of the two interventions to assist them in meeting their needs was justified. The next step, in this process, is to collaborate with the families and assist them in making plans that will facilitate social interaction between families to continue in a format that is comfortable and meaningful to them.

Summary

Data obtained through communication with families that have children experiencing cancer indicated that more support resources were needed in the community. The high number of returned telephone support network information

forms (7 of 9), and the number of families that attended the pizza party (7 of 9) validated that the assessment and analysis of the original data were correct. These two interventions were relevant and increased the social support resources for the local families of children with cancer. Ongoing feedback continues to reinforce the need for rural families to have access to a social support network in their local area.

Implications for Further Study

Living in a rural area can limit the number of resources available to families of children with cancer. In working with families to identify their needs, and assisting them to develop supportive interventions, rural nurses, in collaboration with families, can be instrumental in creating ways to meet perceived needs. The limited availability of established resources does not need to be a hindrance to meeting families support needs. Creativity, ingenuity and collaboration are essential characteristics for both rural nurses and rural cancer families to develop resources where none previously existed.

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APPENDICES

APPENDIX A

INTERVIEW QUESTIONS

Telephone Assessment Questions

1. What do you see as your families social support needs?
2. Do you feel you would benefit from any additional local social support resources for families that have children with cancer?
3. What types of support resources would you like to see available in Helena?
4. What type of social support resources would you and your family be able to use?

APPENDIX B

LETTER OF INTRODUCTION AND NETWORK INFORMATION FORM

Dear ,

I am currently completing my graduate degree in Nursing at Montana State University. Part of the program requirements is a professional project. My project focuses on the social support needs of families with children that have cancer. Expressed by many local families is the desire to have more contact with other families in the area that have either previously or currently experienced childhood cancer.

I am writing for two reasons. The first is to let you know that in response to information received from local families I am developing a telephone network (tree) that can be used to contact other families when you have questions, concerns, or just need to talk to someone that understands what you are going through. I will make the telephone tree available to you, and also to the Pediatric Unit at St. Peter Hospital so it can be given to families of newly diagnosed children.

The second reason is to invite you and your family to a pizza party on Monday March 4, at Godfather Pizza on North Montana Ave. This is a social gathering to thank everyone for participating in my project and a get acquainted party for the local families and kids. I have also obtained guidelines from the National Candlelighters Association about setting up parent support groups. I will bring it to the party for anyone interested in it. Enclosed is an invitation to the party, please RSVP as soon as possible.

If you would like to become part of the telephone network please fill out the enclosed form and sign the attached consent. I need to have both of these returned by February 28th for you to be include in the telephone tree.

Hope to see you at the party and thank you again for participating in my project.

Sincerely,

Information for Telephone Network

Please complete the following form for inclusion in a telephone support network of local families that are or have experienced childhood cancer.

Name of Child _____

Diagnosis _____

Initial treatment center ie. Seattle, Salt Lake, etc _____

Brief description of your child's experience

Any other information you would like included

Parents Names _____

Address _____

Phone _____

APPENDIX C

CONSENT

Consent

Bev Roope, a graduate student at MSU, has permission to use the information provided in a local listing of support resources for families with children that have cancer. I / we understand that the phone number and address will not be included in the written summary of her professional project, but a brief description of our child's' experience may be included.

Signature_____ Date_____

Signature_____ Date_____

APPENDIX D

SUPPORT NETWORK AND RESOURCE LIST

Support Network
March 3, 1996

S.
6 years old
Ewing's Sarcoma
Primary Children's Hospital
Salt Lake City, Utah

I liked the play room at Salt Lake City, PCMC. I didn't like my cancer because it can kill me. When my family cried I got scared inside. I didn't like leaving home and staying in bed at the hospital in Salt Lake and in Helena. I liked Dr. Matlack who got rid of my tumor in July. He did a good job. I did not like the chemo when it made me sick and caused my bones to hurt. I liked riding in the wagon at St. Peters in Helena. I didn't like the food in the Hospitals. It was nice my family could be with me in the hospital much of the time. I don't like to be alone in the hospital.

S.

I did not like the cancer because it kills. It changed my life because some of my activities like gymnastics last summer had to be stopped. Always going to the hospital was not good. It gave me a creepy feeling. Hospitals are not a cheerful place to be.

K.(S. sister)

E.
12 years old
Neurofibrosarcoma
Seattle Children's Hospital

E. was born with neurofibrosarcoma. E. had a large tumor removed from his left flank area when he was 8 years old. It was malignant and since the surgeon did not remove it all, he had another operation in the same area. He then had radiation therapy to the same area for 2 months in Seattle. He later developed several metastatic lesions in both lungs requiring 2 thoracotomies and a thoracoscopy. He also received 6 months of chemotherapy after his initial metastatic lesion was removed. His last thoracotomy in 5/95 revealed extensive metastatic disease in his left lung and diaphragm. He is doing very well at this time. No further treatment is planned. E. is now 12 1/2 years old and he is happy and pain-free. He is taking 2 herbal treatments daily- Essiac and Una de Gato. He has a very positive outlook on life that I think helps us all !!

G.
Neuroblastoma
Salt Lake City

G. was diagnosed in August 1989. He went through 16 months of treatment- some in Helena-some in Salt Lake City. He was in the hospital for a minimum of 6 days for his chemotherapy. When we went to SLC we would sometimes be there for three weeks-he also had radiation treatments. We were having the last treatment when the doctors discovered the main tumor growing again. It was removed surgically-but even with more treatment it continued to grow. What a trooper G. was through all of this!!! He died December 29, 1990.

We established the fund after G. died. The fund helps families with travel expenses when they travel out of town for medical treatment. G.'s memory lives on and on.

K.
3 years old
Germ cell tumor
Seattle

K. first showed signs of no bowel movements for over 1 week. Also, she had a protruding stomach and always wanted to sit back with her gut sticking out. Then had a small bump sticking out in her spine area (down by her tailbone) and we assumed it was a cracked tailbone. She had a 7 cm size tumor (like a small grapefruit) which grew on her tailbone and sacrum. It grew toward her front and up, moving her bladder and cutting off bowel movements. Her tailbone and most of the tumor were removed July, 1994. Then had 4 sets of chemo- 5 days on and 21 days apart. Ended treatment October, 1994. Clear since!!

We put K. into a study in Seattle for this tumor since it is a rare type. As a result, once x number of patients survive her type of treatment a set protocol will be administered so that the kids won't be put into position of being "guinea pigs".

M.
5 years old
Acute Lymphocytic Leukemia
Spokane, Washington

M. was very pale and had a fever a couple of times a week. We were diagnosed with ALL December 9, 1993. It was very difficult and scary in the beginning. Being confined to the

hospital room for a month until counts went up. Steroids, moods, large doses of chemo, hair loss, very scary stuff. But lots of love, care and support from everyone helped us through.

H.

17 years old

Non-Hodgkins Lymphoma

Primary Children's

Salt Lake City, Utah

On January 28, 1993 he was diagnosed with cancer at the age of 14. Our whole world fell apart that day in an instant. However, H. was strong and never gave up, he fought hard to get well even though he had no hair, no energy, and his blood levels sometimes dropped to dangerous levels he was a pretty good trooper through it all. The worst part of all the chemo for H., (I feel) was that awful tasting (Mesna). He would get so upset at the thought of it. However, 3 years and 1 month later H. is currently in remission of that dreadful Lymphoma and I Thank God for that each day! I would be very willing to try and help someone else whose child is ill, too. To well I know what it is like.

W.

11 years old

Acute Lymphocytic Leukemia

Salt Lake City Primary Children's

W. normally is a very strong outgoing active child. All of a sudden she was not walking but a few feet at a time. Leukemia was the last thing my family would have thought. It seemed like the whole world had died when our doctor said the "deadly diagnosis". All I could think or feel was that my baby was going to die. I had no idea that treatment of leukemia has come so far. My daughter, with chemotherapy, was going to beat this deadly disease. In one split second my life was torn apart, then in another second my life was going on. Family's need to be more educated about these childhood diseases, but unfortunately we as humans don't pay attention until it happens to us. If you would like to talk about your experience or learn about our "secrets of success", please call me. Dr. O'Brien in Salt Lake City at Children's Primary Hospital helped me put my family back together again.

Resource List

National Resources

Candlelighters Childhood Cancer Foundation

7910 Woodmont Avenue, Suite 460
Bethesda, MD 20814-3015
301-657-8401 or 1-800-366-2223

American Cancer Society

National Headquarters
1599 Clifton Road, N.E.
Atlanta, GA 30329
(404) 320-3333 or 1-800-ACS-2345

Leukemia Society of America, Inc.

733 Third Avenue
New York, NY 10017
(212) 573-8484 or 1-800-284-4271

Ronald McDonald House Coordinator

c/o Golin Communications, Inc.
500 North Michigan Avenue
Chicago, IL 60614
(312) 836-7100

Special Love, Inc.

117 Youth Development Court
Winchester, VA 22602
(703) 667-3774

Regional Resources

For One Another Cancer Family Network

P.O. Box 6446
Bozeman, Montana 59771
(406) 587-8080

Gary Jacobson Memorial Fund

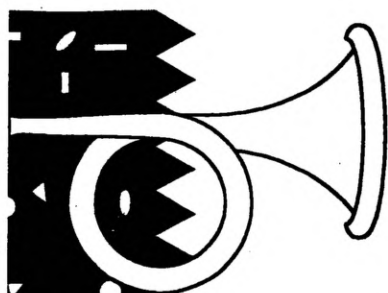
P.O. Box 122
Elliston, Montana, 59728

Children's Oncology Camp Foundation

P.O. Box 7456
Missoula, Montana 59807
(406) 549-5987
1-800-484-5890 ex.CAMP (2267)

APPENDIX E

INVITATION TO PIZZA PARTY



You are invited to a pizza party.....

Who: The whole family

When: March 4, 1996 at 6pm

Where: Godfather's Pizza
Helena, Montana

Why: To get to know one another, eat,
visit, eat, laugh, eat, and share
experiences.

Party hosted by Bev Roope & Dawn
Gormely

See you all there!!!!

Please RSVP
Bev Roope 458-9226

APPENDIX F

EVALUATION TOOL

Telephone Support Network Evaluation Tool*

Please circle the option that most accurately describes your thoughts about the telephone support network.

1. Was the telephone network

- a. Clearly presented
- b. Could be more clearly presented
- c. Not clearly presented

Comments-

2. Is the information provided in the telephone support network helpful?

- a. very helpful
- b. somewhat helpful
- c. not helpful

Comments-

3. Is the telephone support network an effective method to meet your social support needs?

- a. Very effective
- b. Somewhat effective
- c. Not an effective method

Comments-

4. How many times have you used the telephone network?

5. What were the reasons for the phone calls?

* All information provided on this form will be kept confidential. Any further use of the data will be as a group, no individuals will be identified.