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Quality of Life in Grandparents After a Diagnosis of Acute Lymphoblastic Leukemia in Their Grandchild

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QUALITY OF LIFE IN GRANDPARENTS AFTER
A DIAGNOSIS OF ACUTE LYMPHOBLASTIC LEUKEMIA
IN THEIR GRANDCHILD

By

Laura S. Mullins

A THESIS

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

MASTER OF SCIENCE IN NURSING

April 1998

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ABSTRACT

QUALITY OF LIFE IN GRANDPARENTS AFTER A DIAGNOSIS OF ACUTE LYMPHOBLASTIC LEUKEMIA IN THEIR GRANDCHILD

BY

LAURA SUE MULLINS

The purpose of this study was to assess grandparents' perceptions of their quality of life (QOL) after the diagnosis and treatment of acute lymphoblastic leukemia (ALL) in their grandchild. The following questions were addressed: (a) How do grandparents of children with ALL perceive their current QOL; (b) How do grandparents of children with ALL perceive their current QOL has changed since their grandchild was diagnosed; (c) What specific changes in QOL have grandparents experienced since the diagnosis of ALL in their grandchild; (d) What is the grandparents' overall attitude about life with leukemia; (e) Is there a relationship between the length of time since the diagnosis of ALL in their grandchild and the grandparents' current QOL; (f) Is there a relationship

between length of time since the diagnosis of ALL in their grandchild and perceived changes in the grandparents' QOL? Using Roy's Adaptation Model as a theoretical framework, a descriptive research design was used. A convenience sample of 29 grandparents completed the Varricchio-Wright Impact of Leukemia Questionnaire-Grandparents and a Demographic Information Sheet. Measures of central tendency were used to answer the first two research questions. Grandparents' perceived their current QOL to be good to neither good nor poor. They reported their QOL to be the same as prior to ALL in their grandchild. There was no relationship found between length of time from diagnosis and either current QOL or changes in QOL. Implications for nursing practice are discussed.

Dedication

To all grandparents who care for
and support their grandchildren.
May the sacrifices and love which they provide
be acknowledged by those who treat
their grandchildren for their illnesses.

ACKNOWLEDGMENTS

I would like to take this opportunity to thank Sharon Leder, DSN, RN, the chairperson for my thesis. Her leadership and guidance throughout this process was much appreciated. To Colleen Smitherman PhD, RN, and Donna Larson PhD, RN, members of my committee, thank you for your insight and suggestions which strengthened my findings.

Appreciation is also extended to Elizabeth Phillips RN, MSN, for her assistance in entering my data. Linda Scott RN, MSN, is to be commended for her patience and understanding when I came to her late with my data analysis. Her explanation of the results aided in the analysis of this project.

I would also like to thank my co-workers for their support and listening ears throughout my entire MSN program. Without their understanding and encouragement I could not of met my goal.

Last and most importantly I would like to thank my husband, Chuck, for his willingness to allow me to spend endless hours working on this project and never once complaining. Without his knowledge and patience solving my

never ending computer problems this project would never have been completed.

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CHAPTER 1

INTRODUCTION

Most research on the psychosocial aspects of cancer has focused on the diagnosed individual's response to the diagnosis and treatment. This focus fails to acknowledge the impact of illness on the entire family as well as the family's role as a necessary source of support for the diagnosed individual (Cornman, 1993). A diagnosis of acute lymphoblastic leukemia (ALL) in a child is an emotionally devastating event, not only for the child but for all family members (Clark-Steffen, 1993; Cornman, 1993; Jassak, 1992; Moore, Fireman-Kramer & Perin, 1986; Warda, 1992). Regardless of its strengths and weaknesses, the family is the child's most important resource in adapting to cancer (Jassak).

A diagnosis of ALL in a child affects not only the child's parents and siblings but the grandparents as well. When there is a crisis in the family such as ALL in a grandchild, a grandparent will often find him or herself in the hub of it. Giarrusso, Silverstein and Bengtson (1996) found that grandparenthood may be an increasingly significant social role for older people, offering valuable rewards. At the same time, it is important to consider whether a more involved grandparenthood also results in social, economic and psychological costs.

In general, older people may be deeply affected by untoward events that occur in the lives of others to whom they are close. Older people are very vulnerable to the pains caused by stressful events occurring in the lives of other family members, such as injury or illness in a grandchild, the breakup of a grandchild's marriage, or an involuntary job loss (Pearlin & Skaff, 1996).

Grandparents have been an overlooked resource for children with ALL and their families. Grandparents are frequently called upon to assist the families with social, emotional, physical and financial support throughout the treatment of the disease. The amount of time and energy spent caring for the child with ALL or their siblings in the absence of their parents may take its toll over time on the functional level of the grandparents. All of these factors may negatively influence the grandparents' quality of life (QOL). This study attempts to evaluate the effect the diagnosis of ALL in their grandchild has had on the grandparents' QOL.

The incidence of ALL is 1:25,000 children under the age of 14 with a peak incidence between 2 and 5 years of age (Lanzkowsky, 1995). With the treatment regimens of today having improved the survival rates of children with ALL to 78% (Parker, Tong, Bolden & Wingo, 1996), ALL can now be viewed as a serious illness with high hopes of cure. Unfortunately, cancer is usually seen by professionals and

lay persons alike as a universally painful fatal disease (Wright, 1993).

ALL can be a disease of remissions and exacerbations which may significantly impact QOL perceptions. The standard treatment for ALL is anywhere from 2 to 3 years depending on risk factors. Treatment is aggressive with potentially life threatening toxicities both during treatment and for the rest of the child's life.

The family must prepare for the changes occurring as a result of frequent hospitalizations, clinic visits, and the required treatments and observation. Families must adapt to additional sources of stress, such as decreased flexibility, restricted options, increased responsibilities, family separation/isolation, and probably increased financial burden. Even with adequate insurance or state health care assistance, families need to be prepared for potential financial expenses (Moore et al., 1986). Often a mother who is employed outside the home may have to leave her job temporarily or permanently because of the child's health care demands. The costs of travel to the treatment center, lodging, meals, and child care for siblings, in addition to lost income from job absences, soon add up. The social, emotional, physical and financial stressors of this disease affect parents by increasing their vulnerability to the stresses of everyday life (Futcher, 1988).

Parents are viewed as major contributors to the health and well being of their children. Parents provide the

majority of physical care and psychological support for a child with cancer. The quality of parental care and support is directly related to and influenced by the parents' perceptions of their own QOL. These perceptions are bound to change as the social, emotional, physical, and financial stressors occur over the course of the disease.

Wright (1993) identified in her study that parents of a child with cancer perceived their QOL to be good after the diagnosis and treatment of cancer in their child, but not as good as before their child was diagnosed. There was a statistically significant difference in parents' perceptions of their quality of life before and after their child was diagnosed with cancer. The significance of Wright's study was for nurses to recognize these differences and in future research to identify interventions to promote positive QOL in parents of children with cancer.

Grandparents can be strong family supports since they often have time, experience, and access to community resources, plus the motivation to provide both emotional and instrumental support to their children and grandchildren (Vadasy, Fewell & Meyer, 1986). Other grandparents share their experiences in dealing with similar crises, which can enhance the parents' adaptation to their child's illness (Foley, Fochtman & Mooney, 1993; Jassak, 1992).

Grandparents may be the primary care giver for the child with ALL when the parents are working or are otherwise not available. They also may be needed to provide child

care for the siblings while the parents are at the hospital or clinic with the child who has ALL. During times of non-crisis, grandparents may not be as closely involved. When needed, such as during separation and divorce procedures, financial troubles, or illness, grandparents tend to become more actively involved with their grandchildren (Link, 1987).

A baby born in 1900 had a life expectancy of 46.3 years for males and 48.3 years for females (Edelman & Mandle, 1994). At that time, because of the relatively short life expectancy, few children grew up knowing their grandparents. According to the U.S. Bureau of Census statistics in 1993, 33 million persons in the U.S. are over the age of 65 and comprise 13% of the total population. Adults are becoming grandparents at earlier ages and are spending more of their lives in this role than adults in previous generations. On average, women become grandmothers at age 50 years and grandfathers take on this role at age 52; therefore, grand parenthood may span 20 to 30 years (Subcommittee on Human Services, 1982).

Link (1987) found in a review of literature on grandparenting that there is no specific role assigned to grandparents. The role varies depending on the needs, interests and other individual characteristics of the parties involved. Grandparents provide a sense of continuity for their grandchildren and a link with the children's or the parents' past. Barranti (1985) points out

the values of the grandparent role as giving the family a sense of roots, security and stability across the years. Another important contribution of the relationship between grandchild and grandparent is that grandparents are in a position to offer their grandchildren a form of unconditional love that parents, because of responsibilities, are unable to offer. The bonds of intimacy and warmth between the grandparent/grandchild can function as a family resource for the entire family system. The result of this can enhance the QOL for both grandchildren and grandparents.

Grandparents are faced with the burden of coping with their own needs and feelings and with those of their child and the grandchild with leukemia. They suffer two types of grief: for the child who is ill and for their children who are suffering. Grandchildren are supposed to outlive their grandparents, and when there is a potential for that not to happen, the grandparents grieve that possible loss. Parents may find themselves forced to support the mourning grandparents rather than receiving comfort and help in their own grief.

Some grandparents are sources of additional stress to the parents if they find it difficult to believe the diagnosis. Vadasy et al. (1986) found that grandparents often do not have opportunities to talk to the medical professionals who care for the child, making it difficult for grandparents to understand the child's condition and its

implications. Because they lack sufficient information, have limited participation in decision making and have less responsibility for the child's care, some grandparents may not adjust as well as parents (Foley et al., 1993; Hileman, Lackey & Hassanein, 1992).

Problem

Grandparents can serve either as primary family supports or as additional stresses for parents who are trying to cope with major child health problems (Vadasy et al., 1986). The importance of a grandparent to a child with ALL is often overlooked by medical professionals. Understanding grandparents' involvement with the child's family can be important in planning care from a family perspective. Health care providers have devised educational and support programs to assist parents in managing the complex demands of life with childhood ALL and to promote parental QOL. To date, little has been done to identify the effect this diagnosis has on the grandparents' QOL and the support systems which would be helpful in meeting the grandparents' needs. If nurses understand grandparents' perceptions of QOL and how the perceptions may change after the diagnosis of ALL in their grandchild, strategies to promote QOL and enhance family coping could then be explored.

Purpose

The purpose of this study is to assess grandparents' perceptions of their QOL after the diagnosis of ALL in their

grandchild. The following specific questions will be addressed: (a) How do grandparents of children with ALL perceive their current QOL? (b) How do grandparents of children with ALL perceive their current QOL has changed since their grandchild was diagnosed? (c) What specific changes in QOL have grandparents experienced since the diagnosis of ALL in their grandchild? (d) What is the grandparents' overall attitude about life with leukemia? (e) Is there a relationship between the length of time since the diagnosis of ALL in their grandchild and the grandparents' current QOL? (f) Is there a relationship between length of time since the diagnosis of ALL in their grandchild and perceived changes in the grandparents' QOL?

CHAPTER 2

Review of Literature

Conceptual Framework

Roy's Adaptation Model (RAM) states that a person's bio-psycho-social being is in constant interaction with a changing environment; therefore, a person is continually changing and attempting to adapt (Meleis, 1991). A person is conceptualized as having two subsystems for adapting: the regulator and the cognator. The regulator mechanism functions primarily through the autonomic nervous system to organize a reflex action which prepares the individual to respond and adapt to the environment. The regulator mechanism receives stimuli from the internal and external environments, both of which are basically chemical or neural, and receives all input into the central nervous system. The bodily responses, brought about through the chemical-neural-endocrine channels, are fed back as additional stimuli to the regulator system.

The second mechanism is the cognator, which identifies, stores, and relates stimuli so that a symbolic meaning can be attached to the behavior. These processes are influenced by internal and external stimuli and affect the psychomotor choice of response of orientation, approach, avoidance,

flight or hiding as demonstrated in the form of spoken or unspoken words. Failure in either the regulator or the cognator mechanisms result in maladaptation (Meleis, 1991).

The behaviors that result from the regulator and cognator mechanisms can be observed in four categories or adaptive modes: physiological, self-concept, role function, and the interdependence modes. The regulator mechanism is predominantly related to the physiological mode, and the cognator is related to all adaptive modes. It is through these four major categories that responses are carried out and the level of adaptation can be observed (Roy, 1991).

According to Meleis (1991), the physiological mode allows individuals to respond physically to their environment. The five basic needs which function in this mode are activity and rest, nutrition, elimination, oxygenation, and protection. It is the person's physiological behavior that indicates whether the coping mechanisms are able to adapt to the stimuli affecting them. The self-concept mode is related to the need for psychic integrity. Self-concept is defined by a person through significant others, and it includes perceptions of the physical and personal selves. Role function and interdependence modes are focused on the need for social integrity. Role function is viewed as a set of expectations of individuals toward each other. The interdependence between individuals is expressed in ability to love, to respect, to value, and to receive love, respect and value.

These four modes are interrelated, and behavior in one mode may have an effect on or act as a stimulus for one or all of the other modes.

According to Roy's theory, the person's ability to respond positively or to adapt depends on the degree of change taking place and the state of the person coping with the change. Stimuli from the individual's internal and external environment, plus the individual's level of adaptation, function as input into the system. The response to a particular stimulus will be adaptive or ineffective depending upon the person's adaptation level.

Roy (1983) saw adaptation as freeing energy from inadequate or inappropriate coping attempts, thereby promoting health. Health is defined by Roy as a state and a process of being and becoming an integrated and whole person. A whole person is one with the highest possible fulfillment of human potential (Fawcett, 1989). Health then is a reflection of adaptation. The ability individuals have to adapt is reflected in their quality of life. Continued positive outcomes or adaptive behavior would result in high QOL; continued negative outcomes or ineffective behavior would result in a low QOL.

For the purpose of this study, QOL is defined as it was in Wright's (1993) study, as the sum of the individual's perception of his/her adaptation in each of the four modes: physiological, self-concept, interdependence, and role function. QOL is a broad concept embracing more than the

ability to perform certain tasks. The individual's perception of his/her own QOL must be recognized as being of highest importance. Further, the nature of QOL is such that it is continually influenced by interaction with, and adaptation to, stimuli from the individual's internal and/or external environment. A change in one aspect of the environment would impact all other aspects of the individual's environment, thus influencing the individual's QOL.

Grandparents with a grandchild with ALL must adapt to the changes in their lives as a result of this diagnosis. The potential is there for ineffective adaptation in any or all of the four modes identified by Roy thus effecting the QOL of these grandparents. The goal of this study is to identify what changes have occurred and determine if these changes have affected the quality of the grandparents' lives.

Review of Research

Chronic illness in a child and it's effect on the family. Chronic illness is defined as one that is long term (lasting 3 months or more in 1 year) and is either not curable or has residual features that result in limitations in activities of daily living requiring special assistance or adaptation in function or requiring at least 1 month of hospitalization (Jessop & Stein, 1988). According to this definition, ALL would be classified as a chronic illness due to the length of treatment, possibility of recurrence and

potential for long term side effects as a result of the treatment or the disease itself.

Chronic illness within the context of a family is characterized by long-term coping with illness demands superimposed upon the stresses of daily living (Jassak, 1992; Shaw & Halliday, 1992). Parents of children with chronic illness are in need of assistance, both at home and during periods of hospitalizations. This assistance most frequently comes from family (Kupst, Shulman, Honig, Maurer, Morgan & Fochtman, 1982, 1984; Morrow, Carpenter & Hoagland, 1984; Williams, 1993).

Numerous researchers have identified aspects of support and/or family integration as significant to parents' ability to cope with the demands of having a chronically ill child. This was reaffirmed by research done by Ray and Ritchie (1993). Their study examined 29 parents' perceptions of the stressfulness of coping with their chronically ill child's home care. Ray and Ritchie described as most stressful the continual adherence to the child's care regime, the struggle to balance family and care demands, and exacerbations in the child's illness. The three clusters of coping strategies which were most helpful for parents were using family support, maintaining a positive outlook, and ensuring that care was performed. The impact of having or not having a supportive spouse, family or friends was the situational factor mentioned by the greatest number of parents (n=20). The degree of family cooperation, integration, and support

varied considerably among the parents. Descriptions of support as a positive, existing resource outnumbered descriptions of the absence of support as a constraining factor by a 3 to 2 ratio. Parents consistently described family-related features, such as being understanding, cooperative, and flexible and providing aid with chores, as being important, regardless of whether those features were present or absent.

A chronic illness such as cancer has a significant impact on all family members. Cornman's (1993) study of 20 families who had at least one well child and one child with cancer described individual, dyadic, and family responses to childhood cancer. Mothers reported significantly lower self-esteem than fathers which may have been related to the fact that none of the mothers in this study worked outside of the home. They may have been particularly vulnerable to such a meaningful change in the health of their child. Family members were asked to complete three drawings of the family using the Kinetic Family Drawings-Revised guidelines. The majority demonstrated communication problems within the family, as indicated by the presence of objects or barriers between family members. Siblings were the most affected by illness-related variables and visible signs of illness in the patient. Marital adjustment was assessed using the Dyadic Adjustment Scale which found that parents of children with cancer tended to experience heightened marital stress without resorting to divorce. A majority of both mothers

and fathers (53%) reported life events that would indicate that they were at moderate to major risk for major health changes within the subsequent 2 years. The majority of both patients (70%) and siblings (65%) reported life-event scores greater than the upper limit scores for 75% of their age group. Both parents and children scored significantly higher on the Family Environment Scale than the reported norms. This included scores on the conflict subscale in which the children reported a significantly higher degree of conflict than did the parents. The findings of this study reflect the complex nature of families dealing with childhood cancer.

Speechley & Noh (1992) compared 63 parents of childhood cancer survivors to a control sample of parents whose children had not experienced a chronic illness or life-threatening disease and who lived in the neighborhoods of the families with children surviving cancer. It was determined that social support played a key role in determining the extent to which the life strain associated with being a parent of a child cancer survivor induced adverse psychological consequences. The parents living with children surviving cancer and experiencing a lower degree of social support were substantially more distressed (depressed and anxious) than the normative samples.

The purpose of Wright's (1993) study was to describe parents' perceptions of the effect cancer in their child had on parental QOL. Using Roy's Adaptation Model as a

theoretical framework, a descriptive design was used with a convenience sample of 30 parents of children with cancer. The Varricchio-Wright Impact of Cancer Scale-Parents was used to collect data on parental QOL perceptions. The data were clustered into eight groups: parents' current perceptions of QOL in each of Roy's four adaptive modes and parental perceptions of the change in QOL in each adaptive mode since their child was diagnosed with cancer. Results indicated that parents perceived their QOL now as good but significantly poorer than before their child had cancer. Statistically significant differences were found in all four of Roy's adaptive modes.

Coping strategies of families of children with ALL.

The above studies discuss the effects a chronic illness/cancer diagnosis in a child has on the family. Less has been written or researched on children with a diagnosis of ALL, specifically, and its effect on the nuclear family. ALL is a life threatening illness and as a result of its long, aggressive treatment, there are many related stressors which can affect all members of the family (Clark-Steffen, 1993; Cornman, 1993; Fatcher, 1988; Jassak, 1992; Warda, 1992).

Mothers and fathers (n=245) with a child with diabetes, asthma, cardiac conditions, epilepsy or leukemia completed questionnaires to investigate their appraisal of disease-related difficulties and patterns of coping. From these questionnaires Eiser & Havermans (1992) found that in

respect to the differences between diagnostic groups, parents of children with leukemia reported most difficulties in coping, probably due to the unpredictability of the disease. With diseases such as diabetes, cardiac conditions and epilepsy, the natural course of the disease is predictable. In the case of ALL, it often is not. Throughout the treatment there is the risk of serious side effects of drugs and the potential of relapse. For years after therapy has ended, the uncertainty of a recurrence hangs over the parent's head.

Kupst et al. (1982) studied 64 families to assess how well families coped at one year post leukemia diagnosis, to determine which variables related to coping. Based on ratings made by physicians, nurses, psychosocial staff and parents, most families appeared to be coping well with childhood leukemia at one year. Variables which were related to coping included the age of the child, absence of family or marital problems, coping of the other family members, absence of concurrent stresses, occupational status of father and the lack of sibling problems.

At two years post diagnosis, Kupst et al. (1984) restudied 60 of the families of children with acute leukemia. According to ratings made by physicians, nurses, psychosocial staff and themselves, most of families were coping well. Variables which correlated significantly with coping at two years post diagnosis were quality of the marital and family relationships, previous coping with the

illness, coping of other family members, adequacy of support system, lack of additional stressors, open communication within the family and an attitude of living in the present. In response to what was most helpful to the study participants, the most frequent answer was family (n=36).

Kupst & Schulman (1988) resurveyed 43 of the same families they surveyed in 1982 and 1983 and found that these families showed significant improvements in adjustment over time. Correlates of coping were level of family support, quality of the parents' marital relationship, good coping of other family members, lack of other concurrent stresses and open communication within the family.

Fife, Norton & Groom's (1987) research included 34 families. Their study measured the effect a diagnosis of childhood leukemia had on family life and on the lives of individual family members. They identified that families with predominantly stable relationships and adequate support within the family unit were able to maintain their usual QOL over an extended period of time despite the onset of acute stress. The better-functioning families were able to meet the needs of the ill child, while still having energy and interest for other family relationships and activities. However, families with pre-existing problems prior to diagnosis experienced increased deterioration in family life and had difficulty coping.

Grandparents' role with a grandchild with ALL.

According to the research done to date, a diagnosis of

cancer in a child can have a negative effect on the parents and siblings, but no research was found to identify if the grandparents may also be at risk for a negative change in their QOL as a result of ALL in their grandchild. As the previous studies have shown, family support is one of the most important factors in coping with childhood chronic illnesses. Grandparents as an integral part of the extended family are often called upon to assist either with the care of the ill child or their siblings.

Vadasy et al. (1986) surveyed 21 grandparents of special needs children and found that they helped with shopping, errands, or child care. Baby-sitting was the most frequently reported way in which grandparents assisted their grown children (57%). Fifty-eight percent occasionally or regularly provided financial assistance to their grandchild's family. Grandparents often remained involved or took the opportunity to become more active in community groups (76%). This involvement may have provided the child's parents with access to supports within the community. When the grandparents were asked to describe their overall feelings toward their grandchild, 90% wanted to be able to do more to help their grandchild reach his/her full potential.

Burns and Madian (1992) facilitated a support group for grandparents of children with severe disabilities to meet grandparents' needs and to maximize their ability to serve as resources for the parents. Notes were kept on the

discussions of each meeting. The topics were sorted and grouped into themes. One theme was the awareness of the stresses on the young marriage and the grandparents' desire to reduce the stress by providing respite time for the couple. In some cases, grandparents became primary caregivers while mothers struggled to cope with their own distress. Another theme was the struggle to be supportive without being overbearing, providing guidance without being intrusive, and providing love and emotional support when they needed it themselves. Most group members expressed frustration that they were continuing to work past expected retirement age to provide financial support. Emotional issues were of importance to these grandparents experiencing a double sadness, for their grandchild and for their adult child whose burdens seemed so great. The final theme was the need for more information regarding medical conditions and enough information about the condition to become comfortable caretakers and be able to negotiate health and educational systems. Through this group, grandparents developed an increased understanding of the complexity of their role with the child and family.

From the results of the research cited, ALL in a child is a stressful event in the lives of family members. A study by Sherbourne, Meredith, Rogers and Ware (1992) examined the extent to which social support and stressful life events were more or less beneficial for the long-term physical functioning and emotional well being of 1402

chronically ill patients. They found that social support benefits health-related quality of life. Of most interest for this study was the finding that negatively perceived stressful events affect health-related QOL. The occurrence of stressful events was expected to place additional demands on the chronically sick person which might impede their adjustment or accelerate the deterioration of their functioning and well-being. These demands had an immediate negative effect on QOL which persisted over time. As stated in this study, 41% of those aged 54-74 years suffer from one or more chronic conditions, this is of significance considering the age of grandparents.

Summary of the Review of Literature

ALL presents a major challenge to not only the child experiencing the disease, but to the family as well. The literature has documented what effect a diagnosis of ALL in a child has on the QOL of not only the child, but also the parents and siblings. The long term care issues together with the stresses of every day family life place a strain on family and social relationships.

The literature review contains many studies identifying family as one of the single most important source of support and an important mechanism for coping with the illness. Grandparents are frequently called upon to assume supportive roles, such as child care, helping with errands, taking the child to physician appointments and often for financial assistance (Burns & Madian, 1992; Valadsky et al., 1986).

The effect these roles have on the QOL of grandparents is unknown at this time. The diagnosis of ALL in their grandchild is a stressful life event and the potential impact that may have on the QOL of the grandparents and their ability to be supportive to their grandchild or child needs to be identified.

At the present time there is a lack of consistency in the type of tools used to measure QOL. QOL is multidimensional, including physical, emotional and social functioning. The questionnaire used in this study will address QOL according to Roy's four adaptive modes (physiologic, role function, interdependence and self concept). This will give recognition to the importance of considering treatment impact on the entire family, including grandparents, thereby acknowledging the role of the social environment on the grandchild's functioning, and vice versa.

CHAPTER 3

Methodology

This study was modeled after research done by Wright (1993). The purpose of Wright's study was to assess parents' perceptions of changes in their QOL after the diagnosis and treatment of cancer in their child. Wright chose Roy's adaptive system theory as her theoretical framework.

In this study, grandparents were asked to compare their current QOL to their QOL prior to the diagnosis of ALL in their grandchild. The areas of Wright's study which were modified were the population to be studied, the diagnosis, and the length of time from diagnosis. The change in the population involved studying grandparents instead of parents. Only those children with a diagnosis of ALL were included, versus children with all types of cancers. This reduced the effects of different treatments and prognoses.

Wright studied parents' QOL for up to 4 years after the diagnosis of cancer was made in their child. In the present study the time frame was shortened to 3 years from the time of diagnosis. During the treatment of ALL, the first 1-2

years are the most intense, and if the diagnosis and treatment were to have an impact on the grandparents' QOL, it would more than likely occur during that time period. The other factor to consider is that the health of the grandparent may decline over time, and shortening the time frame helps to decrease the chances of that occurring and impacting their QOL.

Design

This study utilized a descriptive research design to identify current QOL and perceived changes in the QOL of grandparents since their grandchild was diagnosed with ALL.

Sample

The convenient sample was selected from a target population of outpatient pediatric hematology/oncology clients in two Southern Michigan clinics. Grandparents' names and addresses were obtained from 43 parents of children with ALL, ages 6 months to 20 years. Grandparents who were stepgrandparents or adoptive grandparents were eligible as well.

Procedure

Parents of children with ALL were identified by the data managers in the pediatric hematology/oncology clinics. The nurse investigator made contact with those parents either in the clinic, by telephone or by mail to explain the purpose of the study. The parents then provided the

addresses of all eligible grandparents, including both maternal and paternal grandparents. A packet was then sent to the grandparents containing a cover letter explaining the study, the research tool, the demographic information form and a self-addressed stamped envelope. Also included was a post card for the grandparents to complete and return separately, if they wanted to receive a summary of the findings. If both grandmother and grandfather were living at the same address, only one survey was sent, to be completed by the primary grandparent caregiver.

The respondent's grandchild must have been undergoing treatment or follow-up care in an outpatient pediatric hematology/oncology clinic and must have been 6 months to 3 years from the time of diagnosis of ALL. The grandparent must have been aware of the ALL diagnosis to be invited to participate in the study. The grandparent had to be able to read and write the English language and be willing to complete the research instrument.

Protection of Human Subjects

Approval to conduct this study was obtained from the Human Subjects Review Committee at Grand Valley State University and from both hospitals where subjects were identified. Participation in this study was voluntary. There were minimal risks involved for the subjects. The decision to participate or not participate would not affect

the child's care or treatment in any way. The subjects' responses were anonymous.

Instruments

Varricchio-Wright Impact of Cancer Questionnaire-Parents. In Wright's (1993) study, data collection involved parental completion of the Varricchio-Wright Impact of Cancer Questionnaire-Parents (VWICS-P) (see Appendix A), a 17 item instrument measuring parental quality of life in each of Roy's domains, and a Demographic Information Form. The VWICS-P is a modification of the Varricchio-Wright Impact of Cancer Scale (VWICS). The content of the VWICS was derived from data obtained from Frank-Stromborg and Wright's (1984) Health Survey. This survey was developed for the purpose of discovering life-style changes due to cancer. The questionnaire consisted of 18 items related to physical changes, 12 items related to psychosocial changes and 5 items that dealt with relationships with health personnel. The VWICS was then modified to form the VWICS-P instrument which probes for parental perceptions of changes in their QOL after their child was diagnosed with cancer. Each item has two parts. The first part of each item asks respondents to describe changes in their QOL since their child had been diagnosed with cancer, using a 3-point scale. The second part of each item asks respondents to describe their current QOL using a 5-point scale.

Based on factor analysis, Wright (1993) determined that the instrument had four subscales which roughly parallel Roy's adaptive modes. These adaptive modes were physiologic, role function, interdependence and self-concept mode.

For use in the parents' study, modifications to the VWICS included changes in wording of each item to indicate the subject was the parent of a child with cancer, not a cancer patient. Considering the nature of the changes to the VWICS, the estimates of reliability and validity of the VWICS were assumed by Wright (1993) for the VWICS-P.

Varricchio-Wright Impact of Leukemia Scale-Grandparents. For this study the Varricchio-Wright Impact of Cancer Scale-Parents (VWICS-P) was modified for the grandparents to the Varricchio-Wright Impact of Leukemia Scale for Grandparents (VWILS-GP) (see Appendix B). The questions on the VWILS-GP were maintained as two parts. The first part of each item asked respondents to identify any perceived changes in their QOL since their grandchild had cancer, using a 3-point scale. The second part of each item asked respondents to describe their current QOL using a 5-point scale.

The questions were changed slightly to be appropriate for the grandparent population. The stem of the first part of each question was changed to read "grandparent" instead

of "parent" and "cancer" was changed to "leukemia." For example instead of "I found out my child had cancer," the item read "I found out my grandchild had leukemia."

A few of the questions were re-worded to enhance clarity. For example, the statement, "My comfort level (The way I feel)" was changed to "My sense of well-being (The way I feel emotionally)." These changes in wording were approved by Wright as being minor and helped to clarify the questions for the grandparents.

The researcher added questions to the questionnaire asking about the relationship the grandparent had with their other grandchildren and their own child. These were not on the VWICS-P since that survey was completed by parents of children with cancer.

Reliability and validity. Content validity for the VWICS-P was established by a panel of experts in oncology nursing according to the criteria proposed by Burns and Grove (1993). Support for construct validity was established using the factor analytic approach suggested by Woods and Catanzano (1988).

Internal consistency of the VWICS was examined by Varricchio, Tse and Wright (1986) using Cronbach's alpha. The alpha coefficients for each factor showed a moderate to high degree of internal consistency, ranging from .67 to .87.

To test internal consistency, a Cronbach's alpha test was run on the VWILS-GP instrument. The alpha coefficient showed a high degree of internal consistency at .8989.

Demographic Data Form

Demographic information was collected for each subject (see Appendix C). This included age, gender, race, number and ages of the grandchildren, age of the grandchildren with ALL, marital status, education, income, occupation, employment status, and the distance in miles the grandparent lived from the grandchild.

CHAPTER 4

Data Analysis

Characteristics of the Subjects

A total of 43 parents were asked to provide the researcher with the addresses of the grandparents of their child with ALL. Thirteen of the parents were contacted by telephone or in person, and 30 parents were contacted by letter. The letter explained the research and asked them to provide the addresses of the grandparents, by mailing them to the researcher. Return postage was paid for by the researcher.

All of the 13 parents contacted by the researcher on the telephone or in person were willing to participate, by providing the grandparents' addresses to the researcher. Of those contacted by letter, only seven parents or 23% responded. No reason was given to the researcher for the failure to respond. The researcher theorizes that the parents who were mailed the letter did not know the researcher, whereas those who were contacted by telephone or in person knew the researcher from the clinic where their children were receiving treatment. In addition, the investigator could explain the study in more detail when speaking directly with the parent. The parents also may

have had more difficulty in declining when approached directly by the investigator.

A total of 39 instruments were mailed to both the maternal and paternal grandparents of children with ALL. Thirty-three instruments were returned of which two were not completed. This resulted in a 79% response rate. One child with ALL did not meet the age eligibility. This left a sample of 30.

Before evaluating the questionnaires for missing data, the researcher determined that any questionnaire with greater than 15% of the data missing would be excluded from the sample. This was the case with one questionnaire. Of the remaining 29 questionnaires it was felt that values which were missing (total of 18) were reasonably random and were not greater than 15% per questionnaire. According to Polit and Hungler (1995), if the missing values are reasonably random then the mean value could be substituted for the missing data. This was done as part of the data analysis.

The age range of the grandparents was 40-76 years (\bar{M} = 61.7 years; SD = 8.68). The subjects were primarily female (86.2%) and Caucasian (85.7%). The remainder were native American (14.3%). Sixty nine per cent of the grandparents were married, 20.7% were widowed and 10.3% were divorced. The marital status of the parents of the child with ALL was similar to that of the grandparents with 59%

being married. The remainder of the parents were divorced (24.1%), never married (13.8%) and widowed (3.4%).

None of the grandparents completed college, but 90% completed high school or trade school. The majority of the grandparents were unemployed (55.2% retired, 3.4% unemployed, 3.4% disabled).

The percentage of grandchildren either living with their grandparent or within 30 miles from their grandparent was 55%. The remainder of the grandchildren lived over 30 miles from their grandparent. Four (14%) of the grandparents saw their grandchildren on a daily basis, four (14%) saw them more than once a week and 10 (35%) saw them weekly. The remainder saw them in varying amounts from once a month to once a year.

The age range of the grandchildren with ALL was 5-20 years. All of the grandparents' grandchildren, including those without ALL, ranged in ages from less than 1 year to 33 years old (see Table 1). The time from diagnosis of ALL in the grandchild to completion of the questionnaire ranged from 6 to 36 months ($\underline{M} = 20.83$, $\underline{SD} = 9.59$).

Table 1

Number and Age of Grandchildren

Characteristic	range	mean	SD
Number of grandchildren	2-38	8.621	6.92
Age of youngest grandchild	.04-16 yrs	5.019	3.948
Age of oldest grandchild	5-33 yrs	18.276	6.686
Age of grandchild with ALL	5-20 yrs	11.517	5.296

Research Question A

How do grandparents of children with ALL perceive their current QOL? The first research question was answered by summing the responses to the second part of each item. The answers to each question utilized a 5-point scale, consisting of the following responses: very good = 1, good = 2, neither good nor poor = 3, poor = 4 or very poor = 5. The possible range of scores were 19 to 95 with 19 being very good and 95 being very poor. The sample's scores ranged from 25-65 (\bar{M} = 42.62, \underline{SD} = 9.35). This result falls between a good to neither good nor poor QOL score.

Research Question B

How do grandparents of children with ALL perceive their current QOL compared with their QOL before their grandchild was diagnosed? The second research question was answered by summing the responses to the first part of each item. The

answers to each question utilized a 3-point scale, consisting of the following responses: better than before = 1, same as before = 2, or not as good as before = 3. The possible range of scores were 19 to 57 with 19 being "better than before" and 57 being "worse than before." The sample's scores ranged from 31-49 ($\underline{M} = 38.38$, $\underline{SD} = 3.26$). This result indicates the sample perceived their QOL to be the same as before their grandchild had ALL.

Research Question C

In an open-ended question grandparents were asked to identify specific changes in their QOL since the diagnosis of ALL in their grandchild. The most common response was that ALL was a mixed blessing in their lives. They were sad that their grandchild had ALL, but the diagnosis of ALL made them appreciate life more. One grandparent stated, "It brought great sadness to my life, but also great joy. Every day with my grandchildren is now all the more precious to me. The true meaning of life and what is important are now evident. I feel the quality of my life is better mentally because I treasure each day more than before." Twelve of the 29 grandparents' statements could be summarized by saying they no longer take life and health for granted and that the diagnosis of ALL had brought their families closer together. Five stated they were sad and anxious and more stressed. (The responses by the grandparents have been listed in the appendices, see Appendix G.)

Research Question D

In an open-ended question grandparents were asked about their overall attitude about life with leukemia. The common theme in their answers was that leukemia makes them sad and they worry. It was heartbreaking for them to watch their grandchild suffer. They have learned to take one day at a time, and it feels like they are living on the edge of a cliff. Their faith in God or praying for their grandchild was important for eight of the grandparents. Two stated they would like to trade places with their grandchild. Two grandparents stated, "Life with cancer sucks!" Another stated, "Although my grandson is in remission, the fear of the disease lingers constantly! Once leukemia has been diagnosed, it becomes a part of every day of my life." (The responses by the grandparents have been listed in the appendices, see Appendix H.)

Research Question E

Is there a relationship between the length of time since the diagnosis of ALL in their grandchild and the grandparents' current QOL? A correlation coefficient identified no statistically significant relationship between length of time since diagnosis and the grandparents' current QOL ($r = -.19$, $p = .36$).

Research Question F

Is there a relationship between length of time since the diagnosis of ALL in their grandchild and perceived changes in the grandparents' QOL? A correlation coefficient

identified no statistically significant relationship between length of time since diagnosis and perceived changes in the grandparents' QOL ($r = -.33$, $p = .11$).

Other Analysis

The individual questions were evaluated to identify if any answers differed from the perceived change in QOL score. In response to the question "How much I sleep now, compared with before I found out my grandchild had leukemia", 52% stated they sleep less now than before, 45% reported no change and 3% slept more.

Another area identified as different was that 48% of the grandparents identified their sense of well-being was not as good as before their grandchild was diagnosed and 45% felt it was the same. Grandparents felt their relationship with their family, children, grandchild with ALL and other grandchildren and friends was either the same as before or better (see Table 2.)

Table 2

Grandparents Relationship with Others

	Better than before	Same as before	Worse than before
Family	35%	59%	6%
My Children	38%	62%	0%
Grandchild with ALL	45%	52%	3%
Other Grandchildren	31%	69%	0%
Friends	14%	79%	7%

Data analysis was also done to note whether there was a difference in QOL for those grandparents who lived within 30 miles of their grandchild with ALL and those who lived greater than 30 miles from their grandchild. An independent t-test was run comparing the two groups current QOL and the perceived change in the grandparents' QOL since the diagnosis of ALL. No significant differences were found (see Table 3).

Table 3

Distance Grandparents Live from Grandchild

Characteristics	<u>n</u>	<u>M</u> (<u>SD</u>)	<u>t</u> -value	2-tail Sig
<u>Current QOL</u>				
<30 miles	16	41.19(9.159)		
			.91	.369
>30 miles	13	44.39(9.64)		
<u>Changes in QOL</u>				
<30 miles	16	38.25(3.733)		
			.23	.817
>30 miles	13	38.54(2.696)		

The data were also analyzed to see how often the two sets of grandparents saw their grandchildren with ALL. Ninety-four per cent of those grandparents living less than 30 miles from their grandchildren saw them once a week or more. Of the grandparents living greater than 30 miles from their grandchild, only 27.3% saw them once a week (see Table 4).

Table 4

How Often the Grandparents Saw Their Grandchild

<u>Grandparents who live <30 miles from grandchild</u>		
Characteristic	frequency	percent
daily	4	25%
more than once a week	4	25%
once a week	7	43.8%
once a month	1	6.3%

<u>Grandparents who live >30 miles from grandchild</u>		
once a week	3	23.1%
once a month	2	15.4%
twice a year	5	38.5%
once a year	1	7.7%
missing	2	15.4%

Chapter 5

Discussion and Implications

Discussion of Findings

As anticipated, grandparents as extended family members are also affected by the diagnosis and treatment of ALL in their grandchild. Although this group of grandparents felt their QOL remained the same after the diagnosis, their responses to the open-ended questions suggest their lives had changed in other ways. The statements by the grandparents reflected their mixed feelings of wishing their grandchild did not have ALL, but they also indicated that it had brought their families closer and made them appreciate life more.

The grandparents who participated in this study must be commended for their 79% response rate. This is an excellent response for a mailed survey. There may be several explanations for this. These grandparents may have been anxious to participate in research which addressed their QOL. They recognize the effect this disease has had not only on their grandchild's parents but on themselves as well.

This study provided for grandparents a potential avenue for their experiences to be recognized and validated.

Even more importantly, the grandparents may have seen this as an opportunity to indirectly help their grandchild or future grandparents of children with ALL. Often grandparents feel they want to do something but do not know what to do. This study may have been seen as an important vehicle for them to feel that they were doing something to benefit others.

Grandparents in this study viewed their overall QOL to be good to neither good nor poor (Question A). Although this is a good overall QOL score, none of the grandparents rated their QOL to be very good. The grandparents' QOL score may be a reflection of the aging process and its effect on their overall QOL. In this study, the ages of the grandparents ranged from 40-76 years (\bar{M} = 61.7 years). Grandparents may have more health related problems of their own, which could also impact their QOL.

Question B of the study asked grandparents to identify if their QOL had changed since their grandchild had been diagnosed with ALL. The grandparents perceived their QOL to be the same as before their grandchild had ALL. Pearlin & Skaff (1996) identified through qualitative interviews that older people are able to maintain a high level of mastery in the face of objectively difficult life circumstances. This

phenomena may explain why these grandparents perceived their QOL to be the same, even in the face of ALL in their grandchild. Past adversities by grandparents may make them more competent in mastering current adversities, such as ALL in their grandchild, and in so doing they did not perceive their QOL had changed.

Roy's Adaptation Model (Fawcett, 1989) would support the grandparents' QOL being the same as prior to the diagnosis of ALL. Roy's theory states that health or QOL is a reflection of adaptation. She noted that being and becoming integrated and whole occurs throughout life. Grandparents because of their ages have had to adapt to many changes or experiences throughout their lifetime. These life experiences may have made them more capable of adapting to the diagnosis of ALL in their grandchild. Positive adaptive behaviors learned over their lifetime could explain why the QOL of these grandparents' may not of changed.

The scores on the questions (questions 12-17) pertaining to the grandparents relationships with family and friends were better than the grandparents overall QOL score. The vast majority of the grandparents (83-93%) felt their relationships were in the good to very good range, as compared to their overall QOL score, of good to neither good nor poor. They also felt their relationships with family and friends were in the better or same as before range (93-

100%). Link (1987) found this to be true that in times of illness, grandparents tend to become more actively involved with their grandchildren.

Forty-eight percent of the grandparents felt their sense of well-being (question 5) was not as good as before the ALL. Because of their lack of sufficient information and knowledge of treatment and it's implications some grandparents may have more difficult understanding and dealing with the diagnosis of ALL. Grandchildren are suppose to outlive their grandparents, and when there is a possibility that may not happen it disrupts one's sense of well being.

Two of the grandparents wrote on their questionnaires that their QOL was worse due to their own health deteriorating. This perceived worsening was not because of their grandchild's ALL. As stated in the study by Sherbourne et al. (1992), 41% of those aged 54-74 years suffer from one or more chronic conditions, which could have a significant impact on the grandparents' overall QOL. It would be difficult to determine if the deterioration is due to the normal aging process or other life occurrences, such as ALL in their grandchild.

Questions C & D were opened-ended questions where grandparents were given the opportunity to identify specific changes in their QOL and state what their overall attitude

about life with leukemia was? Their answers were not surprising, as they found ALL to be a mixed blessing. They were very sad and worried about their grandchild, but it had also brought their family closer together. The responses to the close-ended questions regarding changes in relationships with family were supported by these comments to the open-ended questions.

Eleven of the grandparents stated they were very anxious and worried and felt sad about their grandchild. Faith in God or prayer was mentioned as important 12 times. Religious or spiritual beliefs served as a source of comfort and support, especially in times of crisis. A third of the grandparents stated that they appreciated life more, and they no longer took life and health for granted. Even though this study found the grandparents' QOL to be the same after the diagnosis of ALL in their grandchild, their lives had changed as a result of it. Although they are not happy with their grandchild's ALL, they can adapt and find positive aspects even when experiencing a negative situation.

No relationship was found between length of time since the grandchild was diagnosed and current QOL or changes in the QOL of grandparents (Questions E & F). It was speculated by the researcher that those grandparents whose grandchildren were closer to the time of diagnosis, when the

treatment is more aggressive, would have a lower QOL or report worsening of their QOL than those 3 years from diagnosis. Grandparents were able to adapt and maintain their QOL even though their grandchild may have been having more problems with their treatment.

Limitations

Sample. There were several limitations with this study. The small sample size makes it difficult to draw any global conclusions. The sample was comprised of all Caucasian and native-Americans, and it would be impossible to draw any conclusions about other races or cultures from this research.

The sample in this study was representative of two clinics in southern Michigan. Therefore, it can not be construed to be representative of grandparents in other geographical locations.

Methodology. This study was of a descriptive research design which utilized a questionnaire mailed to the grandparents of grandchildren with ALL. The questionnaire was to be completed by the primary grandparent care provider. As grandmothers are the usual primary care provider, 86% of this sample consisted of grandmothers. Another study could be done to identify whether grandfathers' QOL had been impacted similarly to the grandmothers.

Instrument. An identified weakness of Wright's VWICS-P tool was that the estimates of reliability and validity were assumed and never tested. The VWICS tool, which assessed quality of life in people with a cancer diagnosis, had been tested for content and construct validity. The tool was then revised with slight modifications to the VWICS-P. This tool was modified for the grandparent population of this study. If this tool were to be used again, the researcher would recommend evaluating the tool for content and construct validity. The Cronbach's alpha of .8989 supports the reliability of the instrument with this population.

One weakness of this study was asking the grandparents to recall their QOL prior to the diagnosis of ALL in their grandchild and compare it to their current QOL. For this study, it might have been difficult to recall with full accuracy what their QOL may have been for up to 3 years ago. This is an identified problem with retrospective studies.

Another weakness is the failure to sort out extraneous events or factors which may impact the grandparents' QOL. These factors could include the grandparents' own failing health, retirement, loss of a spouse, etc., which were not related to the diagnosis of ALL in their grandchild.

Application to Practice

Grandparents are an important source of support for the family. Grandparents of today remember when the majority of

children died from ALL and may feel this will be the outcome for their grandchild as well. As nurses, we must take the opportunity when grandparents accompany their grandchild to office visits or to the hospital, to educate them that today the survival rate for children with ALL is approximately 78%. Since grandparents serve as part of the child's support system, they play a significant role for that child. In order to support their grandchildren effectively, grandparents must have up to date information about ALL and the treatment.

Parents should be encouraged to keep grandparents informed about aspects of treatment, especially if they are caring for this child in the parents' absence. Grandparents will imagine things are worse if they are not being kept honestly informed. By not knowing accurate and factual information, the grandparents may imagine situations are worse than they really are. If grandparents are not able to visit the grandchild, this lack of knowledge may ultimately have its effect on the grandparents' QOL.

Parents can be encouraged to bring grandparents to conferences with the physician, when treatments are being discussed. By encouraging good communication between all family members during all stages of the disease process, grandparents can trust that they will be kept informed.

Recommendations for Future Research

As grandparents in today's society hold important roles in the family, health care providers need to identify the effect illness in grandchildren has upon grandparents. Replication of this study with a larger sample size, including other races and additional geographic areas would facilitate being able to generalize results.

If this study were to be repeated, the researcher would recommend doing a longitudinal study. Grandparents' QOL could be evaluated at the time their grandchild was diagnosed and every year for 3 years. The data could then be analyzed to identify if there were significant changes over time. This also would be an ideal opportunity to survey the parents of these children and evaluate the differences between the parents' and grandparents' QOL.

When developing a tool for future studies, it would be important to verify the extent to which the tool adequately captures and reflects the values of older persons in measuring their QOL. The values and importance of various aspects of QOL may be significantly different for grandparents than for younger people, such as the parents, and this would need to be addressed.

Health care providers must identify ways to reach out further to the extended family members to offer them support. Further research needs to be done to identify

interventions to promote positive QOL in grandparents, as they are a major source of support for the children with ALL.

Summary

The burden of a serious illness in a child is not carried by the parents alone, but by the entire family. This study attempted to identify if the diagnosis of ALL in their grandchild affected the grandparents' current QOL and if their QOL had changed since their grandchild was diagnosed. Although no change in QOL was identified in their QOL scores, grandparents' did report their lives had been affected. The diagnosis of ALL served to bring families closer together and facilitated a deeper appreciation for life.

Oncology nurses are in a unique situation to be able to influence the QOL of patients with ALL and their families. As nurses care for these children throughout their cancer illness trajectory, nurses can identify strategies to promote family adaptation to their illness and significantly influence the quality of these families' lives.

APPENDICES

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APPENDIX A



Department of Pediatrics

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Phone: (313) 764-7126
Fax: (313) 936-8520

PEDIATRIC HEMATOLOGY/ONCOLOGY PROGRAM

October 24, 1997

To the parents of :

The Division of Pediatric Hematology/Oncology at the University of Michigan, Mott children's Hospital, has been approached by Laura Mullins, a master's in nursing student, who is doing a research project on the quality of life of grandparents of children with leukemia. You know better than anyone, that parents as well as other family members and friends are affected by the diagnosis and treatment of leukemia in a child. The purpose of her research is to look at the changes, if any, in the quality of life of grandparents of children with leukemia.

If you agree to be a part of this research study, you would be asked to supply the names and addresses of all grandparents of your child. This would include step-grandparents, adoptive grandparents or any person who fills that role for your family. A completely anonymous questionnaire will be sent to your child's grandparents to complete and return to Laura. Your participation, as well as that of the grandparents' is entirely voluntary and in no way should you feel obligated to participate. Not wanting to participate will not affect your child's care in any way. If you chose to participate, complete the enclosed form and return it in the self addressed envelope to Laura and she will mail the questionnaire, with a letter explaining the research to your child's grandparents.

We think this is worthwhile research and the valuable information obtained from this research project will provide information to help nurses understand grandparents of children with leukemia and give us ideas on how to better meet their needs.

Sincerely,


Raymond J. Hutchinson, M.D.
Professor of Pediatrics
Pediatric Hematology/Oncology

Please provide the names and addresses of all grandparents of your child. These may include step-grandparents, adoptive grandparent or any person who fills the role of grandparent for your child. It does not matter how involved the grandparent is with your child or how frequent or infrequent they may see your child. This study will help to tell us how leukemia in your child, effects them as grandparents. If you are talking to your child's grandparent you might notify them that they will receive the questionnaire in the mail.

Name _____
Street _____
City, State, Zip Code _____

Name _____
Street _____
City, State, Zip Code _____

Name _____
Street _____
City, State, Zip Code _____

Name _____
Street _____
City, State, Zip Code _____

After completing this form, please return in self-addressed envelope and mail to Laura Mullins. If you have any questions about grandparent eligibility or questions regarding the study do not hesitate to contact me at 616-341-6350 or in writing at 9072 N. 42nd St. Hickory Corners, Mi.49060.

Thank you for your assistance in this research project.

Sincerely,

Laura Mullins, BSN, RN

APPENDIX B

Appendix B

Dear Research Participant,

I am a nurse conducting a study as a part of my educational requirements for completion of a masters degree in nursing at Grand Valley State University. The purpose of my research is to look at the changes if any in the quality of life of grandparents of children with leukemia. Prior research has identified the needs of parents and siblings of children with leukemia, but I could find no studies to date, addressing issues surrounding grandparents. Your participation in this study will help us learn more about grandparents of children with leukemia and the effects this diagnosis has had on your life. The results of this study will provide information from which interventions to meet the needs of grandparents may be identified and implemented.

Would you please assist me in this study by completing the enclosed questionnaire? Your grandchild was identified by the clinic where she/he is currently receiving their treatment. The child's parents were then contacted by me, either in person or by phone, at which time permission was obtained to contact you by mail.

The questionnaire is completely anonymous, so you are not asked to put your name on it or to identify yourself in any way. If both grandparents are living at this address, the grandparent providing the most care for the child with leukemia or the siblings should complete the forms.

A postage-paid return envelope has been provided for your convenience. I hope that you will take a few minutes to complete and return the questionnaire to me. It should take only about 15-20 minutes of your time. To analyze the information in a timely fashion, I ask that you return the questionnaire within 2 weeks. If you have any questions concerning the research or the questionnaire, I can be reached at 616-341-6350, Monday-Friday at 8 am - 5 pm. If I am unavailable at the time you call, please leave a message and I will be happy to return your call. You may also contact Dr. Paul Huizenga, Chairperson of Human Subjects Review at Grand Valley State University at 616-895-2472 with your questions.

Your participation in this study is entirely voluntary and in no way should you feel obligated to participate. Not wanting to participate will not affect your grandchild's nursing or medical care in any way. If you would like a copy of the summary of the results of this study, please complete the post card provided and mail it separate from the

questionnaire. This will insure confidentiality of your answers. The goal of this research is to help nurses understand grandparents of children with leukemia and give us ideas on how to better meet their needs. I greatly appreciate your assistance in this study.

Sincerely,

Laura Mullins RN, BSN, CPON

If you do not wish to participate, sign your name and return this letter in the envelope provided. Thank you

Name _____

APPENDIX C

IMPACT OF CANCER SCALE - PARENTS

This is a questionnaire about how your child's cancer affects your daily living. We want to know how you feel about some of the changes that have taken place since your child was diagnosed. This will help nurses better understand parents of children with cancer and give us ideas on how to improve care. Not wanting to participate in this study will not affect your child's nursing or medical care.

Directions for the Impact of Cancer Scale-Parents

1. There are two parts to each question.
2. The first part will ask you to compare one part of your life now with how it was before your child had cancer.
3. You will have three (3) answers to choose from.
4. Circle one answer that best describes you.
5. The second part of the question will ask you what you think about that part of your life as it is now.
6. You will have five (5) answers to choose from.
7. Circle one answer that best describes how you feel.
8. There are seventeen (17) questions to answer.

When you are finished with the questionnaire:

Place the questionnaire in the mail using the envelope provided. NO POSTAGE IS NECESSARY. Thank you very much for taking the time and effort to help me with this questionnaire.

Penelope Wright, Ph.D., R.N.

Impact of Cancer Scale-Parents

1. MY PHYSICAL ACTIVITY (How much I can do)

Compared with before I found out my child had cancer, my level of physical activity is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think my physical activity now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

2. MY INTEREST IN FOOD (My appetite)

Compared with before I found out my child had cancer, my appetite is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think my appetite now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

3. MY WEIGHT

Compared with before I found out my child had cancer, my weight is: (circle one answer)

1. More than before
2. Same as before
3. Less than before

I think my weight now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

4. MY SLEEPING HABITS (How much I sleep)

Compared with before I found out my child had cancer, how much I sleep is: (circle one answer)

1. More than before
2. Same as before
3. Less than before

I think how much I sleep now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

5. MY COMFORT LEVEL (The way I feel)

Compared with before I found out my child had cancer, the way I feel is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think the way I feel now is:

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

6. MY PAIN (My discomfort or my hurt)

Compared with before I found out my child had cancer, my discomfort or hurt is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think my discomfort or hurt now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

7. **MY APPEARANCE** (The way I look)

Compared with before I found out my child had cancer, the way I look is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think the way I look now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and I cannot answer.

8. **MY EMPLOYMENT STATUS** (My work or job)

Compared with before I found out my child had cancer, my work or job status is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think my work or job status now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

9. **MY INCOME**

Compared with before I found out my child had cancer, my income is: (circle one answer)

1. More than before
2. Same as before
3. Less than before

I think my income now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

10. MY FAMILY'S LIFESTYLE (The way my family lives)

Compared with before I found out my child had cancer, the way my family lives is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think the way my family lives now is (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

11. MY FEELINGS ABOUT MYSELF (The way I feel about myself)

Compared with before I found out my child had cancer, the way I feel about myself is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think the way I feel about myself is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

12. MY SEX LIFE

Compared with before I found out my child had cancer, my sex life is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think my sex life now is: (circle one answer)

1. Very good.
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

13. MY PARTNER

Compared with before I found out my child had cancer, my partner treats me: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think the way my partner treats me now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

14. MY RELATIONSHIP WITH FAMILY/FRIENDS (The way I get along with my family and friends)

Compared with before I found out my child had cancer, the way I get along with my family or friends is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think the way I get along with my family or friends now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

15. MY RELATIONSHIP WITH MY OTHER CHILDREN

Compared with before I found out my child had cancer, my relationship with my other children is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think my relationship with my other children now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

16. MY PHYSICAL ABILITY (My ability to do things)

Compared with before I found out my child had cancer, my ability to do things is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think my ability to do things now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

17. QUALITY OF LIFE (My life in general)

Compared with before I found out my child had cancer, my life in general is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

I think my life in general now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor bad
4. Bad
5. Very bad

_____ I do not understand the question and cannot answer.

What is your OVERALL ATTITUDE about LIFE WITH CANCER and the EFFECTS OF YOUR CHILD'S TREATMENT?

Please put the completed form in the envelope provided and mail. No postage is required. Thank you for your help.

APPENDIX D

Appendix D

Directions for the Impact of Leukemia Scale-Grandparents

This is a questionnaire about how your grandchild's leukemia affects your daily living. I want to know how you feel about some of the changes that have taken place since your grandchild was diagnosed. If both grandparents are living in the same household, the grandparent providing the most care for the child with leukemia or their siblings should complete the forms. Not wanting to participate in this study will not affect your grandchild's nursing or medical care in any way.

- A. There are a total of 19 questions, consisting of two parts (part A & B).
- B. The first part will ask you to compare one part of your life now with how it was before your grandchild was diagnosed with leukemia.
- C. Circle the one answer that best describes you.
- D. The second part of the question will ask you what you think about that part of your life as it is now.
- E. Circle the one answer that best describes you.
- F. If you are unable to complete a question simply leave it blank or if you have comments about the questions, write them in the space provided.

When you are finished with the questionnaire and have completed the demographic information sheets, place the questionnaire and information sheets in the mail using the stamped envelope provided. If you would like to receive a summary of the findings of this research, please place the post card provided in the mail separate from the questionnaire. Be sure to complete the space provided for your name and address. By doing this it will maintain the confidentiality of your questionnaire.

Thank you very much for taking the time and effort to complete this questionnaire.

Laura Mullins, B.S.N., R.N., C.P.O.N.

IMPACT OF LEUKEMIA SCALE-GRANDPARENTS

1. MY ENERGY LEVEL How much I can do)

A. Compared with before I found out my grandchild had leukemia, my energy level is: (circle one answer)

1. More than before
2. Same as before
3. Less than before

B. I think my energy level now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer the question because _____

2. MY INTEREST IN FOOD (My appetite)

A. Compared with before I found out my grandchild had leukemia, my appetite is (circle one answer)

1. Better than before
2. Same as before
3. Less than before

B. I think my appetite now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer the question because _____

3. MY WEIGHT

A. Compared with before I found out my grandchild had leukemia, my weight is:
(circle one answer)

1. Better than before
2. Same as before
3. Not as good as before

B. I think my weight now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer the question because _____

4. MY ABILITY TO SLEEP (How much I sleep)

A. Compared with before I found out my grandchild had leukemia, how much I sleep is: (circle one answer)

1. More than before
2. Same as before
3. Less than before

B. I think how much I sleep now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

5. MY SENSE OF WELL-BEING (The way I feel emotionally)

A. Compared with before I found out my grandchild had leukemia, the way I feel is: (circle one answer)

1. Better than before
2. Same as before
3. Not as good as before

B. I think the way I feel now is:

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

6. The way I feel physically

A. Compared with before I found out my grandchild had leukemia, I physically feel: (circle one answer)

1. Better than before
2. Same as before
3. Not as good as before

B. At the present time I physically feel: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very Poor

I am unable to answer this question because _____

7. MY APPEARANCE (The way I look)

A. Compared with before I found out my grandchild had leukemia, the way I look is: (circle one answer)

1. Better than before
2. Same as before
3. Not as good as before

B. I think the way I look now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

8. MY EMPLOYMENT STATUS (My work or job performance)

A. Compared with before I found out my grandchild had leukemia, my work or job performance is: (circle one answer)

1. Better than before
2. Same as before
3. Not as good as before

B. I think my work or job performance now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

9. MY FINANCIAL STATUS

A. Compared with before I found out my grandchild had leukemia, my financial status is: (circle one answer)

1. Better than before
2. Same as before
3. Not as good as before

B. I think my financial status now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

10. MY FAMILY'S LIFESTYLE (The way my family lives)

A. Compared with before I found out my grandchild had leukemia, the way my family lives is: (circle one answer)

1. Better than before
2. Same as before
3. Not as good as before

B. I think the way my family lives now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

11. MY INTEREST IN SEX

A. Compared with before I found out my grandchild had leukemia, my interest in sex is: (circle one answer)

1. Better than before
2. Same as before
3. Not as good as before

B. I think my interest in sex now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

12. MY RELATIONSHIP WITH MY PARTNER

A. Compared with before I found out my grandchild had cancer, my relationship with my partner is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

B. I think the way my relationship with my partner now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

13. MY RELATIONSHIP WITH MY FAMILY (The way I get along with my family)

A. Compared with before I found out my grandchild had leukemia, my relationship with my family is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

B. I think my relationship with my family now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

14. MY RELATIONSHIP WITH MY FRIENDS (The way I get along with my friends)

A. Compared with before I found out my grandchild had leukemia, my relationship with my friends is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

B. I think my relationship with my friends now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

15. MY RELATIONSHIP WITH MY CHILDREN

A. Compared with before I found out my grandchild had leukemia, my relationship with my children is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

B. I think my relationship with my children now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

16. MY RELATIONSHIP WITH MY GRANDCHILD WITH LEUKEMIA

A. Compared with before I found out my grandchild had leukemia, my relationship with my grandchild with leukemia is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

B. I think my relationship with my grandchild with leukemia now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

17. MY RELATIONSHIP WITH MY OTHER GRANDCHILDREN

A. Compared with before I found out by grandchild had leukemia, my relationship with my other grandchildren is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

B. I think my relationship with my other grandchildren now is:
(circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

18. MY OVERALL HEALTH

A. Compared with before I found out my grandchild had leukemia my overall health is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

B. I think my overall health is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

19. MY QUALITY OF LIFE (My life in general)

A. Compared with before I found out my grandchild had leukemia, my life in general is: (circle one answer)

1. Better than before
2. Same as before
3. Worse than before

B. I think my life in general now is: (circle one answer)

1. Very good
2. Good
3. Neither good nor poor
4. Poor
5. Very poor

I am unable to answer this question because _____

What has CHANGED in the quality of your life since your grandchild was diagnosed with leukemia?

What is your OVERALL ATTITUDE ABOUT LIFE WITH LEUKEMIA

Please put the completed form in the envelope provided and mail. No postage is required.
Thank you for your help.

LM 4/97

APPENDIX E

Appendix E

Code Number _____

DEMOGRAPHIC INFORMATION SHEET

The following information will help us to understand your background and how it might relate to your current situation. As with all information in this study, the data you provide will be treated confidentially.

(check one or fill in the blank)

1. Your age _____ years
2. Your Gender 1. male _____ 2. female _____
3. Your race 1. _____ Caucasian 2. _____ African American
 3. _____ Hispanic 4. _____ Asian American
 5. _____ Native American 6. _____ Other: _____
4. Number of grandchildren (including step-children) _____
5. Age of oldest grandchild _____ Age of youngest grandchild _____
6. Age of grandchild with Leukemia _____
7. Date your grandchild was diagnosed with Leukemia _____ month _____ year
8. Number of children living in the same household as your grandchild with Leukemia _____
9. Your marital status (check one): 1. _____ Married
 2. _____ Never Married
 3. _____ Separated
 4. _____ Divorced
 5. _____ Widowed

10. Marital status of the parents of your grandchild with Leukemia:

- 1. _____ Married
- 2. _____ Never married
- 3. _____ Separated
- 4. _____ Divorced
- 5. _____ Widowed

11. Your work status (check one):

- 1. _____ Presently employed
- 2. _____ Presently unemployed
- 3. _____ Retired
- 4. _____ Disabled

12. Your occupation _____

13. What was the last grade you completed in school (check one).

- 1. _____ Less than grade 12
- 2. _____ Graduated high school
- 3. _____ Completed trade school
- 4. _____ Completed college
- 5. _____ Completed graduate school

14. The number of miles you live from your grandchild with Leukemia (check one)

- 1. _____ lives with grandchild
- 2. _____ lives within 10 miles
- 3. _____ lives within 30 miles
- 4. _____ lives within 50 miles
- 5. _____ lives within 100 miles
- 6. _____ lives within 300 miles
- 7. _____ lives within or over 1000 miles

15. Since your grandchild was diagnosed with Leukemia, approximately how often do you see your grandchild with Leukemia (check one)

- 1. _____ daily
- 2. _____ more than once a week
- 3. _____ once a week
- 4. _____ once a month
- 5. _____ twice a year
- 6. _____ once a year
- 7. _____ less than once a year

APPENDIX F

Appendix F



May 21, 1997

Laura Mullins, RN, B.S.N., CPON
9072 N. 42nd Street
Hickory Corners, MI 49060

Dear Laura:

I was delighted to receive your modification of the VWICS-P. You have made only minor changes to the original instrument which are necessary for its use by grandparents.

You may either call this instrument a modification of the VWICS-P or the VWICS-G, whichever you please. If it was me, I think I surely would like to complete my Masters study with a research instrument with beginning reliability and validity estimates and would opt for the VWICS-G. It would probably be appropriate to indicate that the VWICS-G is a modification of the VWICS-P.

Good luck in the completion of your work. I look forward to reading the finished product. If I can be of further help, please let me know.

Sincerely,

A black rectangular box redacting the signature of Penelope S. Wright.

Penelope S. Wright, Ph.D., CRNP
Associate Professor

APPENDIX G

Appendix G

Specific Changes in QOL

I'm alot more understanding of alot of things.

We no longer take things for granted.

I think it has made me more aware of how precious life is. Especially a child's life. I guess I took it for granted, that a child would live forever and they don't. These precious children, take their illness, as just something natural that happened and to them it is just an everyday thing. They are very happy and I wish my grandchild wouldn't have gotten ill, but since she did I'm glad we had a chance to experience this illness with her.

Any changes in quality have nothing to do with him.

Not only with our grandchild, but the loss of our son and other medical problems with family I've learned how short and precious life and health is.

I feel sad alot and can't concentrate on work as well as I used to. I am more rushed because I have to go 40 miles out of town once a week to visit my grandchild and that takes a day out of my work week. I cry easily and feel inadequate.

When the phone rings you always think something bad has happened, or when there is a message and their voice doesn't quite sound right, you worry if they're holding something back.

We have always been very close, but daily we are always together now. Very thankful for modern medicine & the doctors & staff at Bronson. I worry alot more now-some times get stressed out. But he's doing just-pray he stays well.

It affects your life more when it is a grandchild.

I moved to S.H. and pace has slowed down and it is better for me. I have another grandchild and a renewed relationship with my daughter.

Having to always be ready to drop any and everything to take him for the endless emergency situations that pop up out of no where. Because his Mom and Dad are divorced, the Mom lives out of state and the Dad needs to work it leaves only me to do the majority of the care for him.

I found out that people I knew were very concerned and immediately informed their churches set up many prayer groups. I believe this has brought all our family closer to each other. Everyone pitched in to make it easier on her and her family. Family really does stick together.

I make sure there is always extra money saved so if she needs or wants something I can help. I'm always thinking and talking about her as she's always on my mind. I also give her quality time anytime she needs it.

More aware of other people with similar illnesses.

I only do what I have to do. No enthusiasm. Some contact with friends but not as much, less desire to be around people. I am a recovering addict and have dropped down to one meeting a week.

A much closer relationship with God, children and grandchildren and friends. He has changed as did most people around him. This made everyone have a deeper appreciation for life in general.

I am much more concerned with the well being of all the members of my children and grandchildren. My family has other family members who have fought and are fighting cancer. But the way I feel now since the leukemia was diagnosed, the concern goes much deeper.

More stress, worry about him

I appreciate waking up everyday! Knowing that my young grandson was a leukemia victim a such a young age has made me appreciate my life and my health. Additionally I try to spend more time with all my grandchildren.

It has brought great sadness to my life, but also great joy. Every day with my grandchildren is now all the more precious to me. My granddaughters courage and faith are amazing.

The true meaning of life and what is important are now evident.

I feel the quality of my life is better mentally because I treasure each day more than before.

Since our grandson has leukemia all of our lives has changed-learning all about the cancer-wishing this would have been us-not him.

Blood pressure shot up-medication created impotence.

More aware of things such as this happening when I never ever thought of this happening in my safe world. I have a much stronger faith in God.

I don't believe there has been any change in QOL. It does however make you more aware how fragile life really is. I do also believe it makes a family feel a little closer.

Every moment counts and should be made "quality ones". You realize how quickly health and life can be taken from you or loved ones. Family comes first more often than it used to. The stress is more than anyone can tell you about. Because my granddaughters parents never married, we as grandparents have had to provide emotional, physical and financial support needed for our daughter and granddaughter. I have learned all the aspects of her care as a back-up should anything happen to her mother. The father doesn't really fully understand and accept the seriousness of her illness. We are "on call" 24 hrs. a day--the car filled with gas, etc.

My grandchild with leukemia lives with us. We appreciate life more.

APPENDIX H

Appendix H

Overall Attitude About Life with Leukemia

It has taught me alot about leukemia. You don't really understand it until it hits you in the face. I've learned not to take things for granted.

We try to show more love and understanding to all illnesses. leukemia has to be taken one day at a time.

I wasn't there during is worst times. My main help for him was watching the other kids so he could have his parents with him. Attitude, I'm sure, would differ from time to time if the child weren't expected to come through this ok. Your first questions should be about the parents' attitude, the child's condition, etc. These affect the grandparents attitudes.

I take each day as it comes. Thankful that our grandchild has handled it so well. Making it easier for the rest of us. But the fact it happened to her & leukemia itself sucks grateful she is doing so well.

I don't understand why children have to suffer so I wish I could trade places with him.

I just feel like my heart is broken and really don't have a good answer for this question.

Because my husband's daughter from his first marriage passed away from leukemia you worry even more. Treatments have changed drastically so even he is in the dark about all the treatments taking place. Then when my daughter tells me of the treatments and how hard they are on my grandson I worry. And when he has a once in a lifetime treatment I worry about what will happen if he should come out of remission. When you go away you hope that nothing happens while you're away. I've noticed how much has changed for my grandson and that his life will never be normal. I get angry with the school system for harassing my daughter because my grandson has

missed so much school. It puts alot of unneeded worry on her shoulders . I'm also amazed by how this has changed my daughter. She had alot of responsibility thrown at her. She has proven to be quite remarkable. The way she has to keep track of all his medications and make sure he doesn't get over exerted. She is remarkable and I'm proud of her.

Life with cancer sucks! But hopefully he's done suffering. We can beat this terrible disease, I'm praying. To watch him suffer just eats at me. That's the worst thing.

You pray that a cure can be found for leukemia & to give all the love that you can. It hurts when you seen another with leukemia.

I don't like it. I can do without it. My grandson is missing out on alot and it makes me feel sad. He probably never will catch up on alot of stuff. It's been awfully hard on my sons family.

It is heartbreaking often filled with disappointments on the child's side and mine. In our case there had been 2 relapses and a BMT. It is very hard to always be encouraging to him, when your heart is breaking. You wait until your alone to cry. We can't make any plans. We just hope God will see him and us through this.

I always look on the positive side of most everything including that I believe she can beat this disease, with lots of love, care and prayers. Loss of her hair was the only thing that really bothered her. Doctors & nurses are wonderful to her.

I can see now first hand what someone goes through. Cancer puts a hold on alot of things. I realize how brave you must be. There must be changes made in your life. There has been alot of progress made in the disease compared to years before.

A very frightening thing, especially for these young children.

His condition now is very good and we all praise God. He still requires treatment, but we still have him and sometimes he doesn't feel well but these times are few and he is a real joy to be with.

It makes you appreciate the time with the child, much more precious. also you find this with all the ones you love.

I believe that faith in God will sustain you no matter what the end results. Also I learned that you can and will sacrifice physically and mentally for the good of the child.

I am so overjoyed that my granddaughter is in remission and doing so well.

Although my grandson is in remission, the fear of the disease lingers constantly! Once leukemia has been diagnosed, it becomes a part of every day of my life.

Very hard on his Mom and Dad.

I feel that when you have a child with leukemia it tends to make you feel a little guilty that you are okay and the child has to go through so much. You always try to do a little extra for this child and spend as much time as possible with her.

I wish it had never happened. But I have a lot of faith in God, that my loving grandson is going to be ok. and be able to live a normal life again, with medical care and prayer.

It is a horrible disease and I would hope someday to have a cure. We are now in the 3rd year with our grandson and praise God he is in remission.

With the good attitude our grandson has we know that he will recover-he is not giving up so this help us as grandparents to know how to cope with this. He help us and we support him.

Very much on the edge. We're very worried about her. We live each day to the fullest.

I wish it had never happened. But I have a lot of faith in God, that my loving grandson is going to be OK. and be able to live a normal life again, with medical care and prayer. It is a horrible disease and I would hope someday to have a cure. We are now in the 3rd year with our grandson and praise God he is in remission.

With the good attitude our grandson has we know that he will recover-he is not giving up so this help us as grandparents to know how to cope with this. He help us and we support him.

It is like living on the edge of a cliff. You never know what will happen. She can be fine on day and next critical. When in public places, you are so aware of the germs

everywhere & how careless people are with their health habits and cleanliness. We have probably become quite paranoid about this. We just take one day at a time--one crisis at a time.

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