## PRE-SCHOOL CHILDREN'S UNDERSTANDING OF CANCER: THE IMPACT OF PARENTAL TEACHING AND LIFE EXPERIENCE

A Thesis

Presented to

The Graduate Faculty of The University of Akron

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

Lindsay C. Varkula

August, 2006

## PRE-SCHOOL CHILDREN'S UNDERSTANDING OF CANCER: THE IMPACT OF PARENTAL TEACHING AND LIFE EXPERIENCE

Lindsay C. Varkula

Thesis

Approved:

Accepted:

Advisor Pamela A. Schulze, Ph.D. Dean of the College James M. Lynn, Ph.D.

Faculty Reader Rose Resler, MA, CCLS Dean of the Graduate School George R. Newkome, Ph.D.

Faculty Reader Kathleen McCue, MA, LSW, CCLS Date

Department Chair Richard Glotzer, Ph.D.

## TABLE OF CONTENTS

	Page
LIST OF TABLES	v
LIST OF FIGURES	vi
CHAPTER	
I. INTRODUCTION	1
II. REVIEW OF THE LITERATURE	5
Piaget's Theory and Pre-school Children	5
Vygotsky's Theory, Pre-school Children, and their Parents	9
Children Enrolled in Pre-school	
Similar Studies	14
Integrating Piaget, Vygotsky, and Other Studies on Illness	
Research Questions	
III. METHODS	19
Participants	19
Procedures	
Coding Categories	
IV. RESULTS	
V. DISCUSSION	
Limitations	

Suggestions for Future Research	. 35
REFERENCES	. 37
APPENDICES	. 40
APPENDIX A. IRB APPROVAL LETTER	41
APPENDIX B. PARENT LETTER	42
APPENDIX C. SCRIPT	. 47

## LIST OF TABLES

Table	Pag	;e

1 Frequency of children's correct responses as a function of parental report ..... 27

## LIST OF FIGURES

Figure		Page
1	Frequency of category use	25

#### CHAPTER I

#### **INTRODUCTION**

With the onset of patient-based and family-based care in the health care field in the twentieth century, many caregivers have been faced with the realization that both the patient and the whole family of an ill individual need a great deal of psychosocial support. According to Corr, Nabe, and Corr (2003), a serious illness and/or hospitalization of an individual member can create prominent changes for the entire family. Routines change drastically or disappear, new barriers in communication arise, individual members are faced with fears and stressors, and the family as a whole is left struggling to cope with the changes. Since each individual in a family copes with stressors in a different way, often they are unable to relate to each other or to find support from one another (Corr et al., 2003). In the absence of support from their family, which is usually the fundamental unit of support in less stressful situations, this struggling population is in need of help and guidance from empathetic and well-trained professionals. Part of the job of these professionals is to work with the family to enable them to function more effectively and to support each other. Several specialized professions have emerged to help support these families in their time of crisis, including social work, psychology, psychiatry, family therapy, and child life. There has also been

the development of special interest groups such as the American Cancer Society, which often focus on a specific disease and provide a range of support and services.

Altogether, the family struggles. A faction of the family that has, however, been largely overlooked until the past fifteen years is the child in the family. Often, in a time of a parent or other loved one's illness, a child would be told that there was nothing wrong with that person and he/she should be quiet and not worry. If a child did attempt to express emotions or ask questions about both the illness and the changes that were occurring in the child's life, he/she might have been promptly scolded and told to stop being "bad" (Corr et al., 2003; McCue, 1994). Parents and other adults also commonly decided not to burden a child with news that could potentially upset him or her. If a parent or adult did not give the child adequate information, that child may have created his or her own version of the truth, perhaps a more ominous and frightening one than actually existed. Therefore, the child was forced to quietly deal with fear and uncertainty. Since those times, specialists in child development have learned that forcing a child to mask emotions and not giving information about the situation is not the ideal course of action in an illness situation. In fact, just the opposite has been found to be true (Corr et al., 2003). Children have a need to know what is happening to their families and to their world in times of great change. Great changes can occur when a family is faced with nearly any serious illness.

The health care and mental health professionals who work with children whose parents have a serious illness need to know what children at each age understand about illness. This will help them effectively design interventions to help these children to cope with their new life challenges. Unfortunately, health care professionals have only

recently recognized the importance of helping a child in such a position. For example, most hospital support is in the form of social work and often only in cases of suspected abuse and neglect. When help is given to children, professionals have had to guess at ways to assist the children, especially younger children, because there is a paucity of research on what healthy children know or understand about illness. Because of this lack of baseline data, health care professionals have been forced to use trial and error and to slowly develop interventions. It is time to provide these professionals with baseline information so that they will be better able to assist the children in their charge.

This study attempted to provide some understanding of young children's concepts of cancer. This particular illness is especially important because of its frequency in society—one in three adults will develop cancer in their lifetime—and the anxiety that a cancer diagnosis produces (Corr et al., 2003). The topic was investigated using typically developing pre-school children (who do not have cancer themselves and who are enrolled in daycare programs) and focused on the cognitive expressions about cancer by these children. It also focused on the perceptions of their parents, their life experiences, and whether parents have taken the opportunity to teach their children about cancer based upon those experiences. Parents were asked to report what they believe their children know about cancer, give a summary of the life experiences of their children that were related to cancer, and describe the teaching they have done with their children about cancer.

In order to better understand the cognitive abilities and limitations of young children that may influence their thinking about illness, it is useful to review several

important theorists whose work is relevant. The two major theories, those by Piaget and Vygotsky, seem to be the most relevant in helping to understand this topic.

#### CHAPTER II

#### **REVIEW OF THE LITERATURE**

#### Piaget's Theory and Pre-school Children

Jean Piaget's Theory of Cognitive Development gives information about what children can cognitively understand at each age, which can be extended to help in understanding pre-school children's knowledge of illness. One of the key elements is his developmental stage model, which organizes cognitive development into four stages. The first stage is sensorimotor (0-2 years) in which infants learn first through reflexes, then through their bodies and their actions on the environment. During this stage, infants learn object permanence (at about eight months), where they realize that a hidden object still exists when it is removed from sight. The second stage is preoperational (2-7 years) in which children learn symbols. These include words as symbols for physical phenomenon and numbers as symbols for amounts. In the third stage, concrete operations (7-11 years), children can complete functions based on those symbols (for example, doing math with numbers). They also learn a concept called conservation, in which they understand that a certain amount of something, no matter its presentation, is equal to that certain amount (not more or less than that amount, as they had previously believed). In the fourth stage, formal operations (11 years and older), children become

capable of abstract thinking (Piaget, 1952; Piaget, 1954; Piaget, 1962; Piaget, 1964; Piaget & Inhelder, 1969).

In describing Piaget's theory, Beilin (1992) states that Piaget adapted many ideas from biology, including the concepts of accommodation and assimilation leading to adaptive behavior. He also contends that constant disequilibrium causes the child to use assimilation and accommodation to strive for equilibration, driving the learning process. Bukatko & Daehlar (1998) gave definitions of these concepts. Assimilation involves using information one already possesses to make sense of the world. Accommodation involves altering one's perceptions (or schemas, Piaget's term) in order to fit in new information with the old knowledge. His stages can explain the behavior of children at a given developmental age (Bukatko & Daehlar, 1998).

Piaget's work was influential in planning and carrying out this study because of his theoretical picture of pre-school children. Since young children are typically in the preoperational stage, he describes them as being primarily affected by physical appearances and extremely focused on their own way of viewing the world. As mentioned previously, Piaget also stresses the importance of a child's actions on his/her environment as influential in his/her development, which is described as the constructivist perspective. Based on Piaget's theory, one might predict that if a child is inquisitive and has intrinsic motivation to find out more about a subject (in this study, cancer) then that child will have a higher probably of learning about that subject. Also, since a child learns by interaction with the environment around him or her, if illness or cancer is a part of that environment in some way, that child will also be more likely to pick up information and understanding of cancer or illness. An interaction between the

learner and the environment might increase the likelihood that the child would have an understanding of the subject. The more learning and interaction that occurs related to that topic in the child's life, the more the child will alter, create, and organize schemas related to the specific topic (through accommodation and assimilation). For children who have some experience with cancer or illness, it is, for the aforementioned reasons, more likely that their understanding of the word "cancer" would be more advanced than that of other children without experience with cancer.

Based closely on the work of Piaget, Bibace and Walsh (1980) created a model of children's developmental concepts of illness. They separated children's understanding of illness into three different periods. Preoperational thought lasts from about 2 to 7 years. In the preoperational thought stage, children are first able to understand illness in terms of phenomeninsm, in which they believe that external, unrelated, concrete phenomenon are the cause of illness. Also in this stage, they sometimes progress in their understanding of illness and believe that it is caused by contagion. The child perceives that illness is caused by proximity between two events that occurs by magic. Concrete operational thought lasts from about 7 to 10 years, and sometimes extends to age 13. In the concrete operational thought period, children come to understand illness as contamination. The child understands that a person, object, or action, external to the child causes the illness. This action/thing is bad or harmful to the body. After mastering the concept of contamination, a child then grows to understand internalization. In internalization, a child perceives illness as having an external cause but as being located inside the body. Formal operational thought lasts from 13 years upward. When a child reaches formal operational thought, that child can have a physiologic concept of illness.

In this, a child understands that the cause of illness is an impaired organ or process and can explain illness as a sequence of events. Finally, after a child reaches a physiologic level, the child can advance to a psychophysiologic level, in which the child realizes that psychologic actions and attitudes affect health and illness.

From this study, one would predict that pre-school children would have an understanding of illness that might include phenomeninsm and contagion. For example, in phenomeninsm, children would likely believe that they are sick because they simply do not feel well. If their understanding has progressed to contagion, children might believe that they have magically contracted an illness by being near someone who is ill. In the study of what pre-school children understand about cancer, it is possible to predict that children's responses would fit into one of those two categories.

Bluebond-Langner (1978) also developed a model that summarized a child's understanding of illness. In this model, however, Bluebond-Langner focused on children who must come to understand their own life-threatening illnesses. In phase 1, the prediagnostic phase, the child becomes aware of changes in the body (primarily physical symptoms) and suspects illness or risk. During phase 1, the child must respond to the physical fact of the disease. In phase 2, the diagnostic phase, the child's disease is diagnosed and given a name. In the diagnostic phase, the child must take steps to cope with the reality of the disease. In phase 3, the chronic phase, the child and family must live with daily tasks like doctor/hospital visits, deal with care regimens, and managing daily stress, especially in times of health crisis. In phase 3, the child must preserve selfconcept and relationships with others in the face of the disease. In phase 4, the terminal phase, death is inevitable. The family and child decide to stop curative treatment and

copes with the illness and their emotional distress. In this final phase, the child must deal with affective and existential spiritual issues created or reactivated by the disease. According to Bluebond-Langner, nearly all children who fit into Piaget's preoperational stage or any subsequent stage, have the developmental abilities to go through these phases, regardless of their age, if they are diagnosed with a life-threatening illness.

Although Bluebond-Langner only specifically studied children who had life threatening illnesses, it seems possible that children who do not have serious illnesses themselves, but have been closely associated with someone who has (such as a parent or other family member), might have a more advanced understanding of disease than suggested by Bibace and Walsh. Because pre-school children might have a more advanced understanding—even on a phase 3 or 4 level in Bluebond-Langner model—that establishes the possibility that they might be further along in the Bibace and Walsh theory. Although this higher amount of understanding is not predicted by Bibace and Walsh, perhaps living through the experience of a close family member's serious disease or even death could increase a child's ability to understand disease.

#### Vygotsky's Theory, Pre-school Children, and their Parents

Although Piaget revolutionized the understanding of cognitive child development, he did not focus on external factors that assist in a child's growth. Unlike Piaget, Vygotsky was inspired by Marxist theory to create a developmental theory that was based on children's social interactions with adults and more capable peers. In this study, Vygotsky's theory is helpful in understanding both what children know about cancer and in understanding parental responses and the parental role in teaching the child. It adds another dimension to how children come to understand cancer in that it gives credit to the people and the environment in which the child is raised for teaching children.

Vygotsky created a socio-cultural theory which emphasized the culture over the individual. Culture, he claimed, provided humans with certain psychological tools to help them to live and to communicate. The most important of these tools was speech, which evolved as an elaborate collection of symbols for things, ideas, and events. For children, developing speech is one of the major tasks of the first few years of life, not only to communicate with and to socialize with others, but also to begin to talk through their own mental problems (first out loud and then internally). Vygotsky believed that these personal dialogues were essential in development.

In addition to his theory on psychological tools, Vygotsky also focused his work on the idea that two separate forces (internal forces and external, cultural forces) drive a child's development. A child who is developing is driven by both intrinsic motivation and by external forces. To explain how these drives combine to help a child develop, Vygotsky described the theoretical concepts of the zone of proximal development (zpd) and scaffolding. According to Vygotsky, the zone of proximal development is the distance between what the child can accomplish without adult assistance and what the child can accomplish with assistance from an adult. Scaffolding occurs when an adult or expert peer teaches something to a child, advancing that child to the next level of understanding (Rogoff, 1990). Bukatko & Daehlar (1998) described Vygotsky's sociocultural theory as being focused on how culture shapes an individual and on the importance of adult guidance in child development.

Chak (2001) discusses differences in perception between adults and children regarding the child's current developmental level and what the child is currently able to learn. An adult might perceive a child to be more advanced than the child actually is or vice versa. The adult might be influenced by stress or values/beliefs and might push a child to do something for which that child is not yet prepared. Or, in this case, parents might make assumptions about what children of a certain age are able to understand or "handle" and therefore not attempt to expose a child to certain information. The child, too, might have unrealistic views of their abilities or of how their parents might be able to help them. Chak also asserts that although the adult may initiate the learning process, the child must be motivated to learn to gain information from the adult. In this study, motivation might drive the child's interest in learning about cancer. Even if a child has a life experience with cancer, the child might not be interested in learning what it means or what could happen because of it. Or, a curious child may never alert a parent or other adult about his/her curiosity. Or, the parents might assume that a lack of apparent inquisitiveness regarding this means that they should not introduce the topic. If a parent is unaware of a child's interest, the parent might choose to refrain from giving information to that child.

Chak (2001) described Vygotsky's theory as justifying adult intervention with a child to help that child grow developmentally. Rogoff (1990) and Schaffer (1991) point out that adults must be sensitive and attuned to the needs of children so that they give the right amount of information (not too advanced or under-stimulating) or the child will not grow. This awareness is essential to detect when young children desire and/or need to learn something about cancer. A child might ask a question or simply give a puzzled

look at the word "cancer" or at some discussion that involves life changes because of a loved one with cancer. If a parent is not sensitive and attentive enough to a child to realize that the child is motivated to learn about cancer, then the parent may miss the opportunity to teach the child. Scaffolding will not occur, and the child's understanding of cancer will not be improved. An adult or parent must employ this policy of being sensitive in every interaction with children, picking up on verbal and non-verbal cues for when to proceed. It is also possible to give a child too much information or too developmentally advanced information and then the child may be too overwhelmed and unable to learn. The child may also develop misconceptions. If, however, a child does not display cues or voice curiosity about cancer, an adult may never have the opportunity to teach the child about it, no matter how sensitive the adult is to that child.

Finally, and perhaps most importantly, Vygotsky has pointed out the importance of culture in a child's growth and development. In American culture, chronic illnesses such as cancer are often associated with death and dying. Also in American culture there is a tendency to avidly avoid open discussion of topics concerning death and dying with anyone, especially young children, because they are considered taboo (Corr et al., 2003). It is common for American adults to value and believe the fact that they are protecting children by not speaking about such topics with them. With the increasing commonality of hospice and its involvement in more dying peoples' lives, this attitude of utter denial and avoidance is being slowly altered, and many people now have the ability to discuss these topics (Corr et al., 2003). Thanatology research (the study of death and dying) has found that in order for people to have a "good death" and for friends and families of deceased loved ones to successfully mourn their losses, it is essential to be able to openly discuss memories and emotions both with a dying person while he/she is still alive and after that person has died (Corr et al., 2003).

For young children in particular, deaths among family and friends can have significant impacts on their lives. Even if they do not have the capability to understand the concept of death in full, these children can be very affected by a death because the mood of their parents can change considerably, there might be activities that are discontinued, or there might be alterations in who takes care of them. Because preoperational children engage in fantasy thinking, it is especially important that they are educated about illness and possibly about loss and the affect it might have on their lives. If not, these children are likely to blame the changes or the sadness of others on themselves and be left with debilitating feelings of guilt. When someone who takes care of them is seriously ill, it is possible that children will think that there will be no one to take care of them when that person is gone, especially for children in single parent homes (McCue, 1994). For all of these reasons, American culture's fear of death and Americans' reactions to death are highly important when considering the study of concepts such as cancer. Therefore, Vygotsky's contributions are essential to this study on young children and cancer (Corr et al., 2003).

#### Children Enrolled in Pre-school

All of the children who participated in this study were enrolled at least part-time in pre-school. Because of this, they may have had ideas about health that are slightly different or perhaps slightly more advanced than children their ages who do not attend pre-school. For example, the children at these day care facilities have learned a great deal about germs. These children have been taught that it is extremely important to wash their hands when they get to school, after they use the bathroom, after they blow their nose, and before they eat meals. They are told that washing their hands with soap and warm water gets the germs off of their hands and helps them to keep from getting sick themselves and from getting other children sick. Therefore, because of these daily routines and the fact that they know the reasons for them, these pre-school children may have a view of health that is different than the view of a child who does not attend preschool.

#### Similar Studies

Although there have been no studies dedicated specifically to how young children understand cancer and how it relates to parents' perceptions, some research has recently been conducted that sheds light on what young children are capable of understanding about disease. Much of this research is based on the theoretical perspective of Piaget. Even more of the completed studies have focused on Piaget and on Bibace's and Walsh's (1979) six stages of illness understanding that show parallel progress to Piaget's developmental stages (Banks, 1990; Bibace & Walsh, 1979; Bibace et al., 1993; Brodie, 1974; Carson et al., 1992; Harbeck & Peterson, 1992; Neuhauser et al., 1977; Peltzer & Prontussananon, 2003; Perrin & Gerrity, 1981; Schonfeld et al., 2001; Williams & Binnie, 2002). Illness-related topics covered by these researchers are extensive and include (but are not limited to) health, physical illness, injury, contagious and noncontagious diseases, causes of diseases, pain, personal adjustment, immanent justice, accidents, locus of control, nutrition, duration of diseases, and recovery from diseases. In general, studies have found, with great consistency, that as a child progresses developmentally, that child's understanding of illness increases and becomes more

sophisticated (Kalish, 1998; Kister & Patterson, 1980; Raman & Winer, 2002; Solomon & Cassimatis, 1999; Whaley, 2000).

Though some excellent research has been done on cognitive- and Piagetianrelated concepts and some of it has included useful information about a child's personal experience and the impact on knowledge, all research on children's understanding of illness has neglected Vygotsky and his followers' contributions, including ideas of parents,' other adults,' or older and more knowledgeable peers' key roles in impacting a child's knowledge about disease.

#### Integrating Piaget, Vygotsky, and Other Studies on Illness

Because of a lack of research or theory that successfully integrates Piagetian ideas, Vygosky's ideas, and the existing illness studies, a new model needs to be created to understand children's concepts of illness that incorporates all of those influences. Several factors may affect a pre-school child's level of understanding about illness. These factors may include a child's basic cognitive abilities, a child's life experience, a child's level of motivation to learn about illness, and a child's access to and receiving of information about illness.

First, according to Piaget, a child in the pre-operational stage tends to have certain basic cognitive abilities and limitations. These abilities are continuously added to and reorganized as the child develops cognitively. In the pre-operational stage, children have mastered enough language and speech abilities that they are able to think by using symbols and internal images. They are able to use language to communicate with peers and adults. The way these children think, however, is not the same as adults. It lacks logic and is often made-up or "magical" in reasoning. These children are also extremely egocentric in that they do not have the ability to understand any perspective but their own.

Second, a child's life experience with illness tends to impact that child's knowledge level. Several researchers have studied this impact on a child's level of understanding about illness (Crisp et al., 1996; Koopman et al., 2004; Siegal & Peterson, 1999). If a particular child has had an illness of any kind, that child might have a different perception of illness than a child who has not had an illness. For example, a child who has been undergoing treatment for leukemia for two years would likely have a different understanding of cancer than a child who does not have leukemia. Also, it can be influential if a child has other experience with illness, which could include illness among close family members, friends, or other more distant acquaintances.

Third, the child must be motivated to learn about the illness. In order for this to happen, the child must have a curiosity about illness (perhaps stemming from some life experience), the cognitive abilities to grasp concepts related to the illness, and an available source of information on the illness (probably the child's parent). Piaget claims that this motivation is intrinsic, and it is the same motivation that drives infants to explore and to make sense of their surroundings. Motivation is what causes a child to act on the environment (perhaps ask a question) in order to improve understanding. Vygotsky claims that parents must not only look for signs of interest or readiness to learn a particular concept, but must challenge children at a level just beyond what the child is currently capable of without assistance. If a child does possess motivation to learn about illness or is unable to articulate questions, that child may be able to influence the parent and alert the parent that it is time to teach this child about illness.

Fourth, a child's interaction with information about illness may be important to that child's understanding of illness. According to Piaget's constructivist theory, children act on their environments in order to increase their understanding of the world. If children have a desire to learn more about illness, they have the power to seek out information (usually by asking their parents or other adults) to satisfy their curiosity. According to Vygotsky's theory, the first qualification for a child to be able to grow in knowledge is the presence of motivation to learn in that child. The second condition is that a parent or other adult is available and willing to assist that child in learning. The parents' ability to devote time and give information to the child can depend on several factors. First, the parent must have an appropriate level of sensitivity to the child's needs and desires. That parent must be aware of the child's desire to learn and that parent must teach the child only what the child is able to understand. Second, what the parent chooses to teach the child is heavily based on values and belief systems, partially determined by the family's culture. A key part of a family's belief system or value system is their opinion about health and illness. Compared to another family, they might have very different beliefs about what children need to know and what they are capable of understanding. For example, if a parent holds a value that a young child should not know the word "cancer," the parent may refuse to impart knowledge of this topic to the child or minimize the importance of the information, even if the child is motivated and cognitively prepared to learn about the topic. Overall, these are the four categories that may make up the total knowledge about a child's understanding of illness.

#### **Research Questions**

The purpose of this research is to improve the knowledge of what normal preschool aged children know about cancer. Whether parents are correct in their assessment of their children's understanding of cancer and whether personal experiences with cancer contribute to this knowledge was also of interest. This research is significant because it provides baseline information that has the potential to assist health care professionals and mental health professionals in the event that they must discuss cancer with children or implement interventions to help children deal with cancer. It may also be influential in designing and implementing programs to teach healthy children about cancer.

This research project is dedicated to improving the extremely small body of research on normal children's knowledge about cancer in relation to parental information and perceptions. How healthy young children (ages four and five) describe and understand the word "cancer" was a topic of interest. Through parental questionnaires, data was collected from the parents of these children including information on them, what they believed their children knew about cancer, and what (if any) experience their children had with cancer. The parents were also asked what, if anything, they chose to tell their child about cancer at that time. The final research questions were as follows:

- (1.) What do four- and five-year-old children know about cancer?
- (2.) What do parents know about their child's understanding of cancer and are parents correct in assessing their child's understanding of cancer?
- (3.) How does personal experience influence children's knowledge?
- (4.) Does parental teaching influence children's knowledge?

## CHAPTER III

#### **METHODS**

#### **Participants**

Participants in this study included twenty-five four- and five-year-old children and their parents. These children and their parents totalled fifty individuals, twenty-five pre-schoolers and twenty-five parents. Twenty mothers and five fathers filled out the parental questionnaire. Eleven of the children were female and fourteen were male. Sixteen of the children were Caucasian, three were Asian-American, four were African-American, and two were more than one race. The sample was obtained by sending letters to parents who had children enrolled at the University of Akron's Center for Child Development, and from two KidsPlay locations, both parts of a chain of day-care centers in the Akron area.

The convenience sample was selected from child care centers that serve a diverse population, including families of different ethnicities and socioeconomic levels. Thus, the sample will be representative of families in the Akron area. All study materials and procedures were approved by the University of Akron Institutional Review Board (see Appendix A), the University of Akron Center for Child Development, and KidsPlay.

#### Procedures

The study was conducted in two parts. After parents received information and consent forms by mail (See Appendix B), those wishing to participate returned the consent and a completed parent questionnaire. From this, both demographic information and information regarding the research questions were gained. Specifically, the survey asked what the parents thought the child knew about cancer, what (if any) encounters the child had with cancer, and whether or not the parents taught the child anything about cancer. The consent forms and parent questionnaires were collected in sealed envelopes at the child care centers to maintain confidentiality.

After receiving parental consent, each child was administered a short interview by the primary investigator. Each interview lasted fewer than five minutes. The interview itself (Appendix C) was designed to be as short as possible and to maximize the comfort level of the child. It was designed through the collaboration of the researcher and two experts on child development. Both of the experts are child life specialists not only with extensive knowledge of child development but also with years of experience working with children and families who are dealing with illness. The potentially difficult question about cancer was sandwiched between easier questions about the familiar topics of fruit and toys. This format was chosen so that the interview would be innocuous for the children, would encourage them to warm-up to the interviewer, would allow them to get used to the format of the questions, and would increase the likelihood of useful responses. In this format, the children knew the answer to at least two of the three questions asked. The interviewer thanked every child for his/her response to each question, regardless of the accuracy of the answer. The researcher conducted a series of pilot interviews to test the appropriateness of the questions, the comfort level of the children, and the likelihood of useful responses. The format of the questions was altered accordingly before the actual data collection began.

Resources were in place through a local family therapeutic center to assist any child or family that may have become upset by any of parts of the study. These resources, though available free of charge, were never utilized.

#### Coding Categories

After the interview data were collected, the children's responses were coded according to major topics that children associated with cancer during the interviews. The author inductively created the coding categories in consultation with professionals with experience working with hospitalized children. These categories were based on the themes that emerged from the responses by the children that were the most prevalent in the data. The goal of this process was to be able to succinctly describe the children's responses.

After the data were collected, major themes that arose from the children's answers were separated into categories for the purpose of coding and analysis. There were seven categories. Out of the twenty-five children interviewed, eleven gave at least one response that indicated that they know something about the word cancer. The coding categories based on how the children identified cancer included:

(a.) "sickness or an illness" – children described cancer as meaning illness or sickness.

"It means you're sick." (Subject 1)

(b.) "bad or harmful" – children described cancer as being bad or harmful without specifying that it was an illness.

"Well, cancer is a bad thing." (Subject 16)

(c.) "specific person" - children referred to a specific person in their description of cancer

(e.g., grandmother, uncle, friend, etc.).

"My grandma and grandpa have a swimming pool this big and wide, deep, feet tall... and they can't catch me because they had surgery." (Subject 5)

(d.) "something medical" - children referred to something medical (e.g., a doctor,

ambulance, hospital, surgery, etc.) in their description of cancer.

"You don't want to have cancer 'cause then you have to stay at the hospital for a few days because you're sick." (Subject 16)

"It means you have to go to the doctor... you have to have a band-aid... not really that shows." (Subject 17)

"They take care of you at the doctor and, and, ummm, they give you surgery" (Subject 13)

(e.) "death or dying" – children referred to death or dying in their description of cancer.

"That means that you're dying." (Subject 19)

(f.) "did not know" - children reported that they did not know the definition of the word

cancer.

(g.) "unrelated response" – children gave a response that seemed to be unrelated.

"Cancer means everyone thinks there's like a fire coming out of the building." (Subject 6)

"It means I go to monster truck with daddy." (Subject 18)

"You shoot it...when you're walking around and you see it then you shoot it." (Subject 21)

Of the eleven who gave at least one response that indicated cancer knowledge, 23

different answers were provided. Most children gave responses that were coded into

more than one category out of categories (a.) through (e.). For example,

"My grandma and grandpa have a swimming pool this big and wide, deep, feet tall... and they can't catch me because they had surgery." (Subject 5)

was coded as both (c.) and (d.) because the child referenced both people (grandma and grandpa) and something medical (surgery).

#### CHAPTER IV

#### RESULTS

The children and parents in this study reported being different genders and races. Using Fisher Exact Tests, there were no significant differences in results for any of the research questions based on the race of the child, on the sex of the child, or on which parent filled out the parental questionnaire.

The first research question looked at finding out what four- and five-year-old children know about cancer. The frequency of responses is displayed in the form of a figure (see Figure 1). Fourteen of the twenty-five children interviewed reported that they either did not know the meaning of cancer or gave the interviewer an unrelated response. When children indicated that they knew something about cancer—they gave one or more responses that fell into categories (a.) through (e.)—the most common response during the interviews was associating cancer with something medical. The second most common response was that cancer was something bad or harmful; the third most common response was that cancer was a sickness or an illness.

#### Frequency of Category Usage



Figure 1 Frequency of Category Usage

The second research question looked at what parents know about the child's understanding of cancer and whether or not they are correct in assessing their child's understanding of cancer. On the parental questionnaire, parents were asked whether or not they believed their children knew anything about cancer. These responses were compared to whether or not the children gave at least one answer from coding categories 1, 2, 3, 4, or 5 (the child saw cancer as an illness, or associated it with something bad, a

person they knew, anything medical, or death and dying) which the principal investigator believed indicated they knew something about cancer. This way, the accuracy of parental estimates of their children was determined. A Fisher's Exact Test showed significant results,  $\chi^2 (1, \underline{N} = 25) = 7.819$ ,  $\underline{p} = .012$ , when children gave at least one response that indicated they knew something about cancer and the parent believed the child would report knowing something about cancer during the interview (see Table 1).

The third research question looked at how personal experience influenced children's knowledge of cancer. Out of 25 families, only ten had reported experience with cancer. For children who gave at least one response that indicated that they knew something about cancer, chi-square analysis did not yield any significant relationship between a child's life experience with cancer and the child's knowledge of cancer (see Table 1). No significant results were obtained when the life experience of the child and each of the coding categories were compared using a chi-square analysis.

The fourth research question looked at whether parental teaching about cancer impacted children's knowledge of cancer. Only three parents out of twenty-five indicated that they taught their children specifically about cancer. The children of these three parents, however, all gave at least one response that indicated that they knew something about cancer. Children who gave at least one response that indicated that they knew something about cancer were more likely to have parents who reported they attempted to teach the child about cancer. A Pearson Chi Square found significant results,  $\chi^2 (1, \underline{N} = 25) = 4.339$ ,  $\underline{p} = .037$  (see Table 1). Data was also analyzed to check for significance in each of the coding categories. Children who had at least one response that fell into the "medical" category were more likely to have parents who attempted to

teach the child about cancer. Fisher's Exact Test yielded significant results,  $\chi^2$  (1, <u>N</u> =

25) = 7.244, <u>p</u> = .024.

Table 1

Frequency of children's correct responses as a function of parental report

	Children did/did not give at least one response that indicated they knew something about cancer	
<u>Accuracy of parents' predictions</u> * Yes No	<u>Yes</u> 10 1	<u>No</u> 5 9
Experience with cancer Yes No	4 7	6 8
<u>Parental teaching</u> * Yes No	3 8	0 14

\*<u>p</u><.05

#### CHAPTER V

#### DISCUSSION

For the first research question, looking at what four- and five-year-old children know about cancer, more than half of the children interviewed reported that they did not know what cancer was or they gave an unrelated response. Of the children who did give at least one response that indicated that they knew something about cancer (eleven children out of twenty-five), the most common responses showed that children of this age link cancer with sickness or illness, report that it is something bad or harmful, or tend to link it to something medical, such as a hospital, surgery, a doctor, or other common medically related people or things. It was a bit surprising that the children rarely referred to actual people who they know who had cancer. Of the ten families that had experience with cancer, only three of the children mentioned someone they knew in association with cancer. It would make sense for young children to associate something relatively unknown (like cancer) with someone or something that is familiar (such as a grandparent or neighbor), but children described cancer in association with "someone they knew" very infrequently. Another highly infrequent category of mention by the children was death or dying. The low frequency of the topic of death by the children might be due to their lack of experience with cancer-related deaths or to a developmentally incomplete understanding of death. Although a few parents voluntarily reported a cancer-related

death in the parent questionnaire, there was no specific question asking whether there was a death as the result of cancer in the child's experience. Therefore, it is difficult to make any conclusions as to the children's connections between cancer and death.

According to the model proposed by Bibace and Walsh (1980), preoperational children (2-7 years of age) understand illness in terms of phenomeninsm, in which they believe that external, often unrelated, concrete phenomenon are the cause of illness. More advanced children in this classification may believe that illness is caused by contagion. Some of the children in this study referred to concrete and tangible things, such as something medical, like a doctor or hospital. These children clearly fit the definition proposed by Bibace and Walsh. There were, however, other children who used terms such as an "illness" or as something "bad" to describe cancer. These children seemed to be presenting a more advanced, less concrete conception of cancer which is not as easily explained by Bibace and Walsh's theory. These children seem to raise the question of the accuracy of Bibace and Walsh's estimations of children's understanding of illness at this age, at least in the case of cancer.

Contrary to the beliefs of Bibace and Walsh, Bluebond-Langner (1978) theorized that children who are faced with their own life-threatening illness can have a much greater, stage-like understanding of illness. This theory describes children as able to progress through a series of four phases as they deal with their own illness. She believed that children who were at least in Piaget's pre-operational stage had the developmental abilities to go through the phases in her model, regardless of their age, if diagnosed with a life-threatening illness. For the purposes of this study, this theory is examined because it may also apply to children who have had to cope with the illness of someone they know. Many of the children in this study seemed to associate illness with the reality of medical themes (e.g., going to the doctor, staying at the hospital, wearing bandages, etc.). In phase three of Bluebond-Langner's model, the child and family deal with daily tasks of doctor/hospital visits, care regimens, and stress, especially in times of health crisis. Although Bibace and Walsh did not believe that children of pre-school age could have a complex understanding of illness, this study seems to show that even if young children have not experienced the illness themselves, their understanding may rank as high as phase three in the Bluebond-Langner model. It is possible that having experienced cancer through an important person in their lives might increase children's ability to understand disease.

The second research question investigated whether or not parents were accurate in their assessments of their children's knowledge of cancer. A Fisher's Exact Test indicated significant results, indicating that parents were able to accurately estimate their children's answers and give an approximation of their knowledge. Interestingly, however, a Fisher's Exact Test did not show significant results when the category of parents attempting to talk/teach their children about cancer was compared to parents who estimated that their children would know something about cancer in the interview. It is interesting that some parents could accurately say that their children knew something about cancer but did not report talking to their children about the subject of cancer. This leads the researcher to wonder how the parents were accurately able to predict their children's knowledge when they never talked to their children about cancer. How were parents able to make this accurate assessment? On what information or inclination was the assessment based? These questions could be addressed in future studies. The third research question looked at how a child's personal experience affects his or her understanding of cancer. Based on Piaget's theory, it was reasonable to predict that if an experience with cancer was part of a child's environment, then a child might be motivated to find out about cancer, increasing that child's probably of knowing about that subject. If cancer had played a part in that child's life in some way, he or she would be more likely to pick up information on and understanding about cancer. Surprisingly, the analysis of the data showed that children's life experiences with cancer did not have a significant impact on whether or not these children gave a response that indicated knowing something about cancer. The lack of significant results may have been because having a life experience with cancer is not enough to cause a child to learn about cancer. Perhaps there are other factors, such as parental teaching, which influence whether or not the child learns about cancer.

It is also possible that the insignificant results were caused by some flaw in the research design. Perhaps, even if children knew something about cancer, they could have been reluctant to report their knowledge to the researcher or they may have reported it in a way that was not meaningful or clear to the researcher. For example, one child responded, "Cancer means everyone thinks there's like a fire coming out of the building" (Subject 6). Another child responded, "It means I go to monster truck with daddy" (Subject 18). It was impossible to tell if the child actually associated a fire (or perhaps a fever or other body system problem) with cancer, or if the other child's father actually did take that child to a monster truck rally when someone had cancer. Both of these children's responses fell into the "unrelated response" category because the researcher was unable to determine whether they were actually associated with cancer or whether

the children were truly giving unrelated responses. It is also possible that the children whose responses fell into the "I don't know" category did have some knowledge of cancer, but simply were unable to articulate it. Because the study was designed to be minimally invasive and minimally upsetting to the children and families and because the primary investigator wanted to avoid making suggestions to children, at points of uncertainty including the aforementioned child responses, participants were not prodded further to describe what they meant by their responses.

The fourth research question looked at whether parental teaching influenced children's knowledge about cancer. Analysis of the data revealed that parental teaching does indeed influence whether children report knowing something about cancer. This result can largely be explained using Vygotsky's theory. According to Vygotsky, learning occurs as a result of an interaction between two people, in this case, parent and child. Two forces may help to drive a child's development. The first is the child's desire and motivation to learn about cancer. The second is a parent's sensitivity to these desires and ability to teach the child in a way that is developmentally appropriate for and meaningful to that child. If the parent's efforts are successful, the child develops a new competency or enhanced understanding through guidance by the parents. In this scaffolding process, manageable information is given by parents at appropriate times through which the child is able to learn (Rogoff, 1990). When children are interested in a topic and parents are sensitive to children's interest and mental capacity, parental teaching can help children to advance in knowledge. When parents in this study were available to teach their children about cancer, presumably using understandable language and methods that were developmentally appropriate, the children may have been better

able to report to the researcher that they knew something about cancer. If, as described by Chak (2001), the parent has the perceptiveness to determine when the child is willing and ready to learn, paired with a child's motivation and desire to learn, the child can then be taught about and come to understand an advanced concept such as cancer.

It is also important to note that seven parents in families where there had been some experience with cancer did not teach their children about cancer. One child who gave a response that indicated some knowledge of cancer had a parent who reported not teaching the child about cancer. For some parents, cancer may be associated with the often taboo subject of death and dying (Corr et al., 2003). The parental questionnaire that was distributed to parents asked why, if they did not choose to teach their children about cancer when it was experienced by someone they knew, they decided to make that choice. Responses from the seven parents who reported not teaching their children about cancer included fears of children not being able to understand, fears of upsetting children, deciding not to actually use the word "cancer" in the explanation, and feeling that the children were too young for such information. If parents decided against actually using the word cancer in their explanations, this could explain the unrelated responses from some of the children during the interviews. Thus, some children may understand the concept of cancer but not know the term "cancer."

#### Limitations

There were several limitations to this study. First, since studies of this kind have not been completed in the past, a new method for gathering pertinent data had to be created. Although this method was designed carefully with the consultation of several practitioners in child development, it still has several flaws. In an effort to minimize the possibility of emotional upset in the children and to make the interaction with the researcher comfortable for them, the questions were kept brief and children were not pressured to explain their answers (or lack thereof).

As with any study, it is possible that the wording of the questions contributed to the findings. Children were asked for their definition of the word "cancer." As previously mentioned, it is possible that some children had some concept of cancer but did not actually know the word. For example, they might have known someone with cancer and have associated it with a related concept (e.g., "something bad," such as mom not being home very often or dad becoming depressed). The child might not, however, have ever learned the word "cancer" and was therefore unable to give an answer to the question even though he or she might have had some knowledge of the concept by a different name (e.g. illness, boo-boo, sickness, etc.). As mentioned previously, it is also possible that those children's answers that had to be interpreted as unrelated responses actually did have something to do with their experiences with cancer.

Although children and parents who participated in this study were recruited from child care centers with diverse populations, the convenience sample used for this study makes the results ungeneralizable. These children's responses may nevertheless serve as an initial step in building our knowledge of young children's understanding of cancer.

The statistical tests and number of participants may have also been problematic. Because of the instrument used to collect the data and the way the data were coded, it was impossible to use statistical tests other than chi square analysis. Because of time and resource constraints, the sample size was relatively small. It should be noted that

significant results with such a small sample may be indicative of a strong effect size. Larger scale investigations are needed in order to confirm these initial findings.

#### Suggestions for Future Research

This study was designed to provide baseline information about what children between the ages of four and five know about cancer and how life experiences and parental involvement influence that knowledge. As far as is known, this is the first study of its kind to examine this particular topic in children of this particular age. There are several avenues of research that can be pursued using this study as a starting point. Changes could be made to the way in which the data are collected. An in-depth interview could be conducted with the parents to gain deeper insight into what the children actually know. A researcher who had knowledge of the family's background before doing an interview with a child, for example, might be able to bring up specific points in a child's life which might give the child clues as to what the concept of "cancer" meant. Methods must be found to understand and study children who have an understanding of the concept of cancer but do not know what the word "cancer" means, are unable to put into words their understanding of cancer, or are unwilling to tell the researcher about cancer experiences.

More research also needs to be conducted looking at why some parents decide to teach their children about cancer and why some decide not to teach their children about cancer. Though some parents gave justifications, it is difficult to determine whether their decisions were made because of values that they held, estimations of their child's capacity to learn or their child's emotionally fragility, or for some other reason. Also, a more phenomological or ethnographic study could follow parents of children with a loved one who has cancer and study how parent-child interactions that may influence children's knowledge of cancer. Not all teaching is verbal, and thus not all teaching strategies will be easy for parents to articulate. In a more naturalistic study, it may be possible to identify other dynamics of parent-child interactions, such as whether parents are able to take advantage of "teachable moments" and teaching within the zone of proximal development.

It might be possible to study parents who believe that children should not be told about cancer and then attempt an educational intervention with them. Parents might be educated on some of the benefits of teaching their children about cancer at an appropriate time. Afterward, children could be measured for their level of understanding of what was happening in their families and their levels of happiness or feelings of safety. As mentioned earlier, not keeping the child informed as to what is going on in his life and leaving it to his imagination to decide why certain changes are occurring in his world may be harmful to the child, especially a young child.

In conclusion, it is important to investigate young children's understanding of the topic of cancer. Because cancer is frequently touching the lives of young children today, their abilities to understand it, the impact of life experiences with it, and the effects of parental teaching can be useful in a variety of academic and clinical settings.

#### REFERENCES

- Banks, Ellen. (1990). Concepts of health and sickness of preschool and school-aged children. *Children's Health Care*, 19(1), 43-48.
- Beilin, Harry. (1992). Piaget's enduring contribution to developmental psychology. *Developmental Psychology*, 28(2), 191-204.
- Bibace, R., Sagrin, J., & Dyl, J. (1998). The heuristic value of Werner's co-existence concept of development. *Journal of Applied Developmental Psychology*, 19(1), 153-163.
- Bibace, R. & Walsh, M. (1980). Development of children's concepts of illness. *Pediatrics*, 66(6), 912-917.
- Bluebond-Langner, M. (1978). The private world of dying children. Princeton, NJ: Princeton University Press.
- Brodie, Barbara. (1974). Views of healthy children toward illness. *American Journal of Public Health*, 64(12), 1156-1159.
- Bukatko & Daehler. (1998). *Child development: A thematic approach* (3rd ed.). Boston, MA: Houghton Mifflin Company.
- Carson, D., Gravley, J., & Council, J. (1992). Children's prehospitalization conceptions of illness, cognitive development, and personal adjustment. *Children's Health Care*, *21*(2), 103-110.
- Chak, Amy. (2001). Adult sensitivity to children's learning in the zone of proximal development. *Journal for the Theory of Social Behaviour*, *31*(4), 383-395.
- Corr, C. A., Nabe, C. M., & Corr, C. M. (2003). Death and dying, life and living (4th ed.). Belmont, CA: Wadsworth & Thompson Learning Inc.
- Crisp, J., Ungerer, J., & Goodnow, J. (1996). The impact of experience on children's understanding of illness. *Journal of Pediatric Psychology*, 21(1), 57-72.
- Doka, K. J. (1993). Living with life-threatening illness: A guide for patients, families, and caregivers. Lexington, MA: Lexington Books.

- Kalish, Charles. (1998). Young children's predictions of illness: Failure to recognize probabilistic causation. *Developmental Psychology*, *34*(5), 1046-1058.
- Kister, M. & Patterson, C. (1980). Children's conceptions of the causes of illness: Understanding of contagion and use of immanent justice. *Child Development*, 51, 839-846.
- Koopman, H. M., Baars, R. M., Chaplin, J., & Zwinderman, K. H. (2004). Illness through the eyes of the child: The development of children's understanding of the causes of illness. *Parent Education and Counseling*, 55, 363-370.
- McCue, Kathleen. (1994). *How to help children through a parent's serious illness*. New York, NY: St. Martin's Press.
- Miller, P. H. (1993). *Theories of developmental psychology* (3rd ed.). New York, NY: Freeman.
- Neuhauser, C., Amsterdam, B., Hines, P., & Steward, M. (1978). Children's concepts of healing: Cognitive development and locus of control factors. *American Journal of Orthopsychiatry*, 48(2), 335-341.
- Peltzer, K. & Promtussananon, S. (2003). Black South African children's understanding of health and illness: Colds, chicken pox, broken arms and aids. *Child: Care, Health & Development, 29*(5), 385-393.
- Perrin, E. & Gerrity, S. (1981). There's a demon in your belly: Children's understanding of illness. *Pediatrics*, 67(6), 841-849.
- Piaget, J. (1952). *The origins of intelligence in children*. New York, NY: International Universities Press.
- Piaget, J. (1954). The construction of reality in the child. New York, NY: Basic Books.
- Piaget, J. (1962). Play, dreams, and imitation in childhood. New York, NY: Norton.
- Piaget, J. (1964). The moral judgment of a child. New York, NY: Free Press.
- Piaget, J. & Inhelder, B. (1969). *The psychology of the child*. New York, NY: Basic Books.
- Raman, L. & Winer, G. (2002). Children's and adults' understanding of illness: Evidence in support of a coexistence model. *Genetic, Social, and General Psychology Monographs*, 128(4), 325-355.

- Rogoff, B. (1990). Apprenticeship in Thinking: Cognitive Development in Social Context. New York, NY: Oxford University Press.
- Schonfeld, D., Johnson, S., Perrin, E., L'Hare, L., & Cicchetti, D. (1993). Understanding of acquired immunodeficiency syndrome by elementary school children—A developmental survey. *Pediatrics*, 92(3), 389-395.
- Shayer, Michael. (2003). Not just Piaget; not just Vygotsky, and certainly not Vygotsky as alternative to Piaget. *Learning and instruction*, 13, 465-485.
- Siegal, M. & Peterson, C. (2002). Children's understanding of biology and health. Cambridge, England: Cambridge University Press.
- Siegler, R., & Ellis, S. (1996). Piaget on childhood. *Psychological Science*, 7(4), 211-215.
- Solomon, G., & Cassimatis, N. (1999). On facts and conceptual systems: Young children's integration of their understandings of germs and contagion. *Developmental Psychology*, 35(1), 113-126.
- Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes*. M. Cole (Ed.), Cambridge, MA: Harvard University Press.
- Whaley, Bryan. (2000). Explaining illness to children: Advancing theory and research by determining message content. *Health Communication*, *11*(2), 185-193.
- Williams, J. & Binnie, L. (2002). Children's concepts of illness: And intervention to improve knowledge. *British Journal of Health Psychology*, 7, 129-147.

APPENDICES

#### APPENDIX A

#### IRB APPROVAL LETTER



Office of Research Services and Sponsored Programs Akron, OH 44325-2102

(330) 972-7666 Office (330) 972-6281 Fax

December 28, 2004

Lindsay Varkula 1261 Weathervane Lane Apt. 2D Akron, Ohio 44313

Ms. Varkula:

The University of Akron's Institutional Review Board for the Protection of Human Subjects (IRB) completed a review of the protocol entitled "Understanding of Cancer: How Pre-School-Aged Children Describe Cancer and the Accuracy of Parents' Assessment of Children's Knowledge". The IRB application number assigned to this project is **20041212**.

The protocol qualified for Expedited Review and was approved on December 22, 2004. The protocol represents minimal risk to subjects and matches the following federal category for expedited review:

(7) Research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation or quality assurance methodologies

This approval is valid until December 22, 2005 or until modifications are proposed to the project protocol, whichever may occur first. In either instance, an Application for Continuing Review must be completed and submitted to the IRB.

Enclosed is a copy of the informed consent document, which the IRB has approved for your use in this research. A copy of this document must be submitted with any application for continuation of this project.

Please note that within one month of the expiration date of this approval, the IRB will forward an annual review reminder notice to you by email, as a courtesy. Nevertheless, it is your responsibility as principal investigator to remember the renewal date of your protocol's review. Please submit your continuation application at least two weeks prior to the renewal date, to insure the IRB has sufficient time to complete the review.

Please retain this letter for your files. If the research is being conducted for a master's thesis or doctoral dissertation, you must file a copy of this letter with the thesis or dissertation.

Sincerely. - Ale certa

Sharon McWhorter, Associate Director

Cc: Richard Glotzer, Department Chair Rose Resler, Advisor Phil Allen, IRB Chair

The University of Akron is an Equal Education and Employment Institution

#### APPENDIX B

#### PARENT LETTER

#### (Date)

Dear Parents,

You and your child are invited to participate in a research study on pre-school children's understanding of cancer. I am conducting this study as part of my work toward a Masters degree in the Department of Family and Consumer Sciences at the University of Akron. My co-researchers include Rose Resler, from the University of Akron's Department of Family and Consumer Sciences, and Kathleen McCue, from The Gathering Place. Yetty Michael, director of the University of Akron's Child Development Center, and Julie Rand, director of Kids Play will oversee the project in their child care centers.

The purpose of the study is to gain an understanding of what four and five-year-old children know about cancer. With the rate of cancer increasing, more and more children are exposed to parents or other relatives with cancer. At this time, we are unsure of the level of understanding that children have at the pre-school level, and this study will be of great assistance in determining the appropriate level of intervention to provide for young children regarding the topic of cancer. Gaining this basic understanding is important because it can give health care professionals a baseline understanding of what children know at this age, which could improve strategies and enhance abilities to talk to a child about cancer.

Participation is voluntary. You may revoke your decision to participate and your child's permission to participate at any time. Your child will be free to withdraw from the interview at any point. The anticipated risks or benefits of this study for you and your

child are minimal to none. Each child will participate in one short interview (lasting about 10 minutes), which will take place in your child's day care center. I, as primary investigator, will conduct the interviews, and your child will have the option of having a teacher's aid with whom he/she is familiar accompany him/her to the interview. The interviews will be tape recorded to insure that we are able to accurately capture your child's answers. Parents will be asked to provide information on your family's experience with cancer on a short form entitled "Family Questionnaire."

I will be asking your child simple and general questions about his/her understanding of a fruit, of a toy, and of cancer. Some children may have difficult memories associated with cancer. In the event that you or your child become upset by the interview and/or survey, The Gathering Place, a caring community organization seeking to provide support, education and empowerment to those touched by cancer, is available at no charge to assist with any negative feelings or reactions that may arise as a result of this study. Your child's confidentiality will be protected and the information gathered on the Parent Questionnaire will also be kept confidential. Any identifying information collected will be kept in a secure location and only the researchers will have access to the data. Participants will not be individually identified in any publication or presentation of the research results. Your signed assent form will be kept separate from the data, and no one will be able to link responses to you or to your child. All identifying information will be destroyed at the end of the study.

The University of Akron Institutional Review Board for the Protection of Human Subjects has approved this study. For more information about your rights as a human research participant, please contact Ms. Sharon Mc Whorter, Associate Director, Research Services at 330-972-7666 or 1-888-232-8790 (toll-free). The administration of the University of Akron's Center for Child Development and the administration of Kids Play have also approved this research. In order to obtain accurate results from our study, it is extremely important that you, as parents, do not do anything to alter your child's understanding of cancer between now and the time of your child's interview. We ask that you do not discuss the subject any more than you normally would, because any additional instruction could reduce our ability to get an accurate idea of what children at this age typically know. You and your child will be in no way judged on your knowledge about the subject of cancer or on how you have chosen to discuss or not to discuss it in your household. Your child will be praised for his/her input no matter what information is given as a response, and we do not intend to attempt to teach your child anything about cancer.

If you have any other questions about the project, please do not hesitate to call me at 216-374-9163, my co-investigators, or the day care center directors:

Rose Resler, School of Family and Consumer Sciences at the University of Akron: 330-972-8040

Kathleen McCue, Children's Program Director at The Gathering Place: 216-595-9546

Yetty Michael, Director of the University of Akron Center for Child Development: 330-972-8211

Julie Rand, Director of KidsPlay Child Care Centers: 330-896-4506

If you are willing to participate, **please sign the consent form on the next page, fill out the Parent Questionnaire, and return BOTH of these documents** to the Center for Child Development front desk by **November 18, 2005,** using the enclosed envelope. If you decline to participate, please fill out the next page and return. Thank you for your help!

Sincerely,

Lindsay Varkula Graduate Student, Department of Family and Consumer Sciences, The University of Akron

#### **\*\*PLEASE RETURN THIS FORM\*\***

#### CONSENT AGREEMENT:

I, the undersigned, hereby give permission to have my child participate in the above study on pre-school children's understanding of cancer. I also give permission for my responses to the parent questionnaire to be used in the study.

I understand that I have the right to revoke this consent at any time.

Signature of Parent/Guardian

Date

Name of Child (please print)

Please return **this form and the parent questionnaire** in the enclosed envelope (seal for your privacy) to the front desk of the Center for Child Development by **Friday**, **November 18th, 2005**.

# PLEASE RETURN THIS FORM EVEN IF YOU **DECLINE** TO PARTICIPATE IN THE STUDY:

I DO NOT give permission for my child, \_\_\_\_\_\_, to participate in the above study on pre-school children's understanding of cancer.

Thank you!

## Family Questionnaire

Thank you for your participation in this study. Please complete this form as fully and as accurately as you can.

 Date:
 Completed by:

 Relationship to child:
 Child's Name:

1. Do you think your child has ever heard the word "cancer"?

- Yes \_\_\_\_ No \_\_\_\_
- If yes, what do you think your child knows or understands about cancer?

2. Has someone close to you and your child had an experience with cancer during your child's lifetime?

- No \_\_\_\_ Yes \_\_\_\_
- If yes:

  - Age of your child during the experience:

o At that time, did you attempt to teach your child about cancer?

Yes \_\_\_\_ No \_\_\_\_

Why or why not? \_\_\_\_\_

- 3. Demographic Information:
  - Your child's age: \_\_\_\_\_
  - Ethnic Background
    - \_\_\_\_ African American
    - \_\_\_\_ Asian American
    - \_\_\_\_ Caucasian/White
    - \_\_\_\_ Hispanic/Latino
    - \_\_\_\_ Other: \_\_\_\_\_

#### APPENDIX C

#### SCRIPT

## Script for Child Interviews (text in italics <u>not</u> actually spoken to the participant during the interview)

Hello, my name is \_\_\_\_\_. I am going to ask you some questions about 3 different words. All I want you to do is answer each question as best as you can. If you do not want to answer a question, don't have to and you may return to your class at any time. Here are your three questions:

#### *Question 1:* What is a banana?

- a. *Child gives answer:* 
  - If child's response is "I don't know," go on to 1.b.
  - If child gives any other response, skip to next question.

#### b. Have you ever heard the word "banana"?

- \_\_\_\_Yes \_\_\_\_No
- If child's response to 1.b. is "yes," ask child 1.c.
- If child's response to 1.b. is "no," skip to next question.

c. When you heard the word "banana," what were people talking about? Good job! Thank you.

#### *Question 2:* What is cancer?

- a. *Child gives answer:* 
  - If child's response is "I don't know," go on to 2.b.
  - If child gives any other response:
    - 2.a.1. Can you tell me any more about (*child's response to 2.a.*)?
      - If child has answered 2.c. in his/her response to 2.a., skip to next question
      - If child has not answered 2.c. in his/her response to 2.a. then skip to 2.c.

b. Have you ever heard the word "cancer"?

\_\_\_\_Yes \_\_\_\_No

- If child's response to 2.b. is "yes," go on to 2.c.
- If child's response to 2.b. is "no," skip to 2.d.

c. When you heard the word "cancer," what were people talking about? Thank you! Good job.

*Question 3:* What is a ball?

a. *Child gives answer*:

- If child's response is "I don't know," go on to 3.b.
- If child gives any other response, end interview.

#### b. Have you ever heard the word "ball"?

\_\_\_\_Yes \_\_\_\_No

- If child's response to 3.b. is "yes," ask child 3.c.
- If child's response to 3.b. is "no," end interview

c. When you heard the word "ball," what were people talking about? Good job! Thank you.