Spiritual Dimension: As Described by Chronically Ill School Age Children

by

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THESIS

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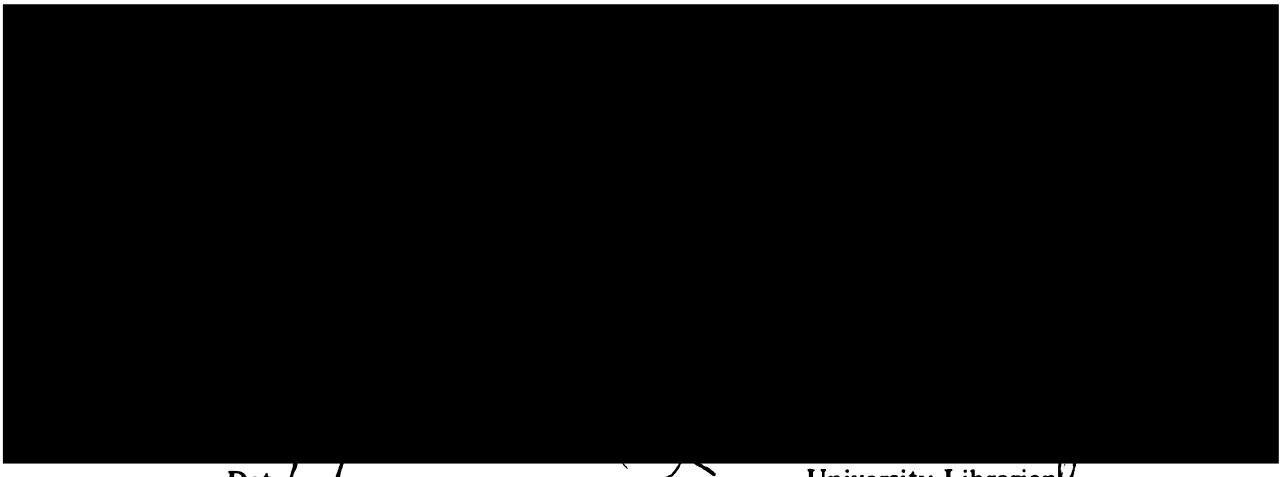

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Abstract

This exploratory descriptive field study sought to answer the question: How do chronically ill school age children in a specific situation describe God and do they associate God to their illness? The purpose of this pilot study was to collect and document information on how chronically ill school age children described God and if their descriptions associated God to their illness. A convenience sample of seven school age children were interviewed. The children were between six and twelve years of age, chronically ill with renal tubular acidosis (but in a period of wellness), and attending school on a regular basis. All were from a Judeo-Christian background with parents and family with similar religious affiliations.

A twelve question, open ended, semi-structured interview was conducted with the consenting child, following a brief demonstration to determine the cognitive level of the child. The interview took approximately fifteen to twenty minutes and was conducted by the primary researcher.

The findings indicated that these chronically ill school age children do have a spiritual dimension that they utilize as a resource to cope with illness and life. These children described God as a loving, benevolent, friend and person who had the power to heal, protect, and help them. The results showed that these children relate God to their illness in a positive way.

"Let us also lay aside every encumbrance, and the sin which so easily entangles us, and let us run with endurance the race that is set before us..."

Hebrews 12:1

As in any challenge we face in life, God brings those along side us to help encourage and sustain us in our endeavor. The credit for a work of this magnitude cannot justly go to the author alone. Therefore, I wish to acknowledge those people who have come along side me to run this part of my race in life. Those who did help me know who they are and have my everlasting gratitude. Your reward awaits you in heaven.

If this thesis on the "Spiritual Dimension: As Described by Chronically Ill School Age Children" encourages even one health professional to sincerely consider how children's spirituality can help their health and healing; then the effort of all those who contributed to this research was well spent. I will be forever thankful.

Melinda Sarmiento

Table of Contents

List of Tables

Chapter I

Introduction

The concept of wholistic health care views man as a psycho-social, physical, and spiritual being. Chronic illness poses major threats in these three areas for school age children. On the psycho-social and physical plane these threats may include: fear of rejection, poor self concept and body image, disrupted school attendance, changes in achievable goals, pain, physical symptoms, decreased physical functioning, and frequent hospital admissions (Isaacs & McElroy, 1980; Mattsson, 1972). Threats to the spiritual realm may involve conflict with morality and causality of illness. The child may feel guilt due to past behaviors and view God as punishing him or her with the illness (Brazelton, 1953). On the other hand, children may see God as a benevolent person, who plays a significant role in helping them (Goldman, 1964).

In light of these threats, Mattsson (1972) states that with chronic illness these threats are possibly more acute for school age children than for adults. School age children may be vulnerable and easily threatened because of limited coping abilities due to lack of experience. Avenues available to help chronically ill children cope and adjust to their illness should be found and utilized so that these children can continue to grow and develop into normal, functioning human beings.

The wholistic health care concept states that all three areas: psycho-social, physical, and spiritual components, need to be dealt with during illness. All three areas need to be brought in balance and harmony in order to develop a healthy, functioning system (Westberg, 1961). Yet, of the above three components as viewed by the wholistic health care approach, the spiritual dimension is the least studied and understood.

Because of the lack of information, much preliminary research is necessary in order to understand the spiritual dimension and how it effects chronically ill school age children. This exploratory study is a beginning for health professionals toward knowledge of the spiritual realm of children and how it relates to their illness.

Statement of the Problem

This study sought to answer the question: How do chronically ill school age children in a specific situation describe God and do they associate God to their illness?

Purpose and Significance

The purpose of this pilot study was to collect and document information on how chronically ill school age children described God. This effort would lay a foundation from which health professionals could begin to understand what these children think about in their spiritual dimension.

If in fact school age children with chronic illnesses associate God with their illness, then further studies

could be planned to categorize these associations. Also, other studies could test for any presence of spiritual needs specific to chronically ill children. Once the presence of spiritual needs was demonstrated, further studies could then evaluate whether providing spiritual care, by health professionals would in fact improve well behavior in chronically ill children. This would be significant in improving compliance, coping abilities and adjustment to chronic illness in this group of children.

Definition of Terms

God: whatever the child describes God to be.

Chronically ill: those subjects with chronic renal tubular acidosis since birth and able to attend school on a regular basis.

School age: children within the ages of six to twelve years who demonstrate an ability to think on the concrete operational level.

Specific situation: children from a Judeo-Christian background whose parents and/or family are active church attenders of the same religious affiliation.

Assumptions

1.) Children from a Judeo-Christian background will have been exposed to spiritual beliefs which would allow a concept of God to be developed.

2.) Children who respond appropriately to a space/volume demonstration will be in the concrete operational stage of development.

3.) Children's spiritual beliefs are influenced by family, church school and church.

4.) Accurate information will be given to the interviewer.

Limitations of the Study

1.) The small sample size limits the generalizability of the study beyond the sample population.

2.) Only subjects with a specific chronic illness were studied, therefore limiting the generalizability to other chronic illnesses.

3.) Need for parental consent could have caused parents to bias their children's responses.

4.) Lack of a control group prevents any comparison to children from non-religious backgrounds or other religious affiliations.

Chapter II

Overview of Relevant Research

Various sources define wholistic health care as dealing with the psycho-social, physical, and spiritual being (Frankl, 1963; Jourard, 1964; Kron, 1976; Goldberg, 1980). Frankl (1963) asserts that in order to provide an effective comprehensive health care approach, health professionals need to address the spiritual needs of their patients. Moreover, nursing literature stresses the need for spiritual assessment and intervention for patients receiving care (Piepgras, 1968; Pumphrey, 1967; Brooks, 1969; Dickson, 1973).

Studies attest to the fact that adults and children have a spiritual dimension with spiritual needs. Although school age children are still unable to view their world in abstract concepts, they can describe God in concrete operational terms. Piaget (1929) concluded from his studies that young children have a spiritual dimension and do think about God.

There have been several studies done on the spiritual dimension of normal healthy children by various child developmentalists. The major studies and the findings on spiritual development and conceptions in children will be discussed in this chapter. These past studies have been few and exploratory descriptive in design. Data was obtained by means of interviews and questionnaires. Also, only healthy children from the United States and England were

studied. Since virtually no studies have been done on children's spiritual dimensions in relation to their illness or hospitalization, the major adult studies in this area, appropriate for this study will be discussed.

Harms (1974) studied American children from various religious backgrounds in public and private schools. He reported on their descriptions of what God looked like. His results suggested that children view God in three stages: 1) 3 - 6 year olds viewed God in terms of "fairy tales;" 2) 7 - 10 year olds viewed God in terms influenced by home, church school, and church functions; and 3) adolescents were too individualistic in their descriptions to classify their responses. No further studies have replicated this study to validate the existence of these three stages of spiritual development in children.

In a series of studies by Goldman (1962, 1964) on children from various religious backgrounds, he revealed that there are stages in children's religious and theological maturing that relate to their normal cognitive development. For example, by 6 - 11 years of age (cognitive operational stage) children's religious ideas are concrete, physical, and literal (Goldman, 1964). At this stage they enjoy church school, singing in church and saying prayers by themselves.

Elkind (1964) interviewed 800 children from various religious backgrounds on their religious identity and found that these children interpret their religious identity in

terms of their level of comprehension. He stated that inevitably children will be exposed to religious ideas before they are able to assimilate them. Furthermore, their parents and the church will influence their spiritual perceptions. In another study, Elkind (1967) empirically tested the development of prayer in 160 elementary school children between the ages of 6 - 12 years. The results suggested that the development of prayer and mental thoughts moved from subjective toward objective with increasing age. This research indicated that school age children were able to express their spirituality in terms of their level of development.

The spiritual dimension has been studied in both the acutely ill and chronically ill adult. Also, the effects of spiritual resources on adults in response to chronic illness have been studied. Crooge and Levine (1972) studied adult males recovering from heart attacks. The results described religion as playing a supportive role in providing a resource and assisting in their adjustment to their condition. Florell (1973) tested 22 matched paired, orthopedic surgery, adult patients assigned to a control and experimental group. The experimental group received spiritual counseling by the hospital chaplaincy whereas the control group received no counseling. The non-control group showed marked improvement in health, compliance and well behavior. These studies suggested that adults utilized their spiritual dimension as a resource during illness.

Yet, the majority of studies evaluating children's spiritual perceptions and needs have only investigated healthy children. In addition, Cully (1979) discussed the different spiritual needs of Christian children throughout the Piaget and Erikson stages of development. These studies revealed how healthy children utilized their spiritual dimension in understanding and dealing with their world. Research dealing with chronically ill children addressed only the psycho-social and physical dimensions (Isaacs & McElroy, 1980; Child et al., 1980; Mattsson, 1976). These studies suggested a need for further evaluation of the spiritual dimension in children with fatal and acute illnesses (Waechter, 1979; Kubler-Ross, 1975).

Even this limited amount of exploratory descriptive research on the spiritual dimension of children suggested a need for further evaluation of the spiritual dimension in children. Although the adult studies on how the spiritual dimension is utilized in illness lends itself to this area interest in children, there is still need for further evaluation of spiritual needs in adults.

Theoretical Framework

Developmental Theory

Jean Piaget's cognitive developmental theory will be the basic framework for studying the cognitive ability of chronically ill school age children from 6 - 12 years (Meier, 1969; Piaget, 1926; Richmond, 1970). It is important to understand the theory of the development of thought

processes in these children in order to analyze their responses to questions dealing with their spiritual dimension. As Ronald Goldman (1964) points out "Religious thinking is no different from other kinds of thinking, but is merely thinking about religious things."

Piaget's developmental theory proceeds in stages and periods delineated by chronological ages. He stresses that cognitive development is a continuous process with no sudden changes or jumps from one stage to another (Meier, 1969). The length of time a child stays in one stage and adapts to the next stage differs with individuals. The age demarcation for the stages only serves as a guideline and is by no means absolute.

The learning process itself occurs through the child's experiences. Throughout this learning process, children build within themselves a model of the external world through direct contact, and through the process of assimilation and accommodation. With each new experience, the child must add or internalize it, which is assimilation. Furthermore, in order to incorporate this new experience, the child must modify his/her thought processes, which is accommodation (Richmond, 1970). The use of these two processes is called adaptation which leads to learning and development. This adaptive process brings the child to an equilibrium state and prepares him/her to move on to the next stage (Meier, 1969).

Piaget's first stage of development is the sensorimotor stage; from birth to two years. The learning process

is dependent upon the senses. The child is very egocentric and has difficulty differentiating the self from others in the environment.

The second stage, the preoperational stage is from two to seven years. The most important development is that the child now can speak. Through language, the child begins to socialize. These children still tend to be egocentric and have little objectivity. They are unable to hold more than one element of a situation in their mind at a time. Also, they utilize fantasy and intuition to explain events.

As children move from egocentricity and are able to differentiate self from others, and self from the environment, the process of reasoning begins to develop. Intuition is replaced by operational thinking, but is confined to actual experienced situations because the child has not yet built a mental model of the world. This type of thinking is the concrete operational stage.

Children at this stage are able to understand the principles of conservation (volume can be the same when the shape changes) and reversibility (two sticks of identical length are the same size even when the position is changed). This ability to think in terms of conservation and reversibility is significant for this age because it enables the child to be taught through formal education. Children in this stage experiment constantly and begin to classify and reason in relation to their observations. Explanations of events are now in terms of physical and

natural causes. Although children may understand the physical and natural causes, they may have difficulty verbalizing this until later in this stage.

Finally a transition from concrete to operational thinking to abstract thinking begins to emerge at the ages of eleven or twelve. This type of conceptualization is called the formal operational stage. The adolescent can now construct theories and philosophize into adulthood. Inductive and deductive thinking is developed and formal logic is possible.

Development of the Spiritual Dimension

The second theory base for this study is the development of religious or spiritual thinking in children from six to twelve years. Piaget (1929), Elkind (1964, 1967, 1974), and Goldman (1962, 1964) studied this aspect in concrete operational children and provided a substantial theory base for chronically ill school age children from Judeo-Christian backgrounds.

As previously mentioned, school age children six to twelve years are in a concrete operational level. Therefore, these children's religious ideas are concrete, literal and physical. Religious ideas are understood on the level of their logical thinking. They translate spiritual and religious abstract generalizations into concrete terms. In other words, they draw upon every day experiences and concepts in life to understand God (Goldman, 1964).

Most children at six years of age are beginning to assimilate and accommodate religious terms and are building

up their own spiritual dimension. Children's beliefs in God are seen to derive from their parents (Piaget, 1929). Young children view their parents as God-like, but around six years, children discover that their parents are not perfect and cannot do all things. At this point, children realize that there is a figure respected and revered by the adult world and they begin to accept the God of their culture. At this age, the development of the concept of God is possible (Bovet, 1928). Also, they are able to now understand religion through religious instruction (Elkind, 1974).

In addition, much of the school age children's ideas, rules and morals are derived from adults (parents) in order to obtain approval necessary for security (Piaget, 1929; Elkind, 1974). Feelings of guilt are often connected with the fear of God in that children learn from the Bible that God punishes those who are bad (Brazelton, 1953). Yet, at the same time God is thought of in terms of his attributes: goodness, kindness, or as the creator (Elkind, 1964).

This age group views God and religious ideas on an anthrophomorphic level. They think about God in either human or fantasy terms (Piaget, 1929). They often describe God in human form with special powers like superman. He is often viewed as a person who is in control and can perform magic (Goldman, 1964). These children are unable to differentiate God from Jesus and are confused about these figures. They see no real significance about church attendance and

do not seem to connect it with daily life. They regard church as a special building with "holy" associations (Goldman, 1964).

Prayer is another important area in children's religious and spiritual understanding. They are interested in religion and involve themselves in prayer and service with seriousness about God as well as asking for things. Prayers are still basically egocentric at this age. Between the ages of nine to thirteen years, children begin to understand prayer as a kind of private communication with God. Prayer becomes more altruistic and general. They find some satisfaction in prayer and at this age they often learn set prayers by heart.

Thus, this age group from six to twelve years have distinct characteristics in their concrete operational stage. Their understanding and cognition of the spiritual realm is dependent on their level of thinking. Unlike adults who can think in the abstract, these children understand God and religious ideas on a concrete, literal and physical level. Yet this level of cognition does not deny them a spiritual dimension. They are still able to think about spiritual things.

Chronic Renal Tubular Acidosis

Chronic renal tubular acidosis is a metabolic disease involving the kidneys. The glumerular filtration rate of plasma HCO_3 and pH levels are affected leading to hypochloremia and acidosis. Primary chronic renal tubular acidosis

is an autosomal recessive trait that is genetically transmitted. Symptoms of the disease may present themselves at birth or later in the child's life. Most common effects of the disease are characterized by short stature, growth retardation, hypochloremia, polyuria, acidosis, and dehydration. Treatment of choice is oral alkali therapy with or without potassium supplement for the child's lifetime. Adequate control of the illness should be monitored by periodic evaluations. As long as the child is on a controlled oral alkali treatment plan, normal growth, development and health can be maintained (Vagham, et al., 1979).

Chapter III

Research Method

An exploratory field research method was chosen for this pilot study due to the limited research available in this area. A descriptive design was selected to document the responses of the subjects to an open ended, semi-structured interview.

Study Sample

A. Human Subjects Assurance

Permission to conduct this study through the University of California, San Francisco School of Nursing was obtained from the Human Subjects Committee at the University of California, San Francisco.

B. Criteria for Sample Selection

A convenience sample of ten subjects meeting the following criteria were selected for the study:

1.) 6 - 12 years of age

2.) having chronic renal tubular acidosis

3.) attending school on a regular basis

4.) coming from a Judeo-Christian background

5.) both parents and children associate with similar religious affiliation

Ages 6 - 12 years was chosen because this is the age range where children are considered to be in the concrete operational stage of development. Chronic renal tubular acidosis was chosen because the convenient sample population available for the study had this particular chronic

illness. Regular school attendance was necessary to assure that the subjects were in the least amount of distress, stable in their medical treatment and of sound mind to enable them to comprehend the interview questions. Subjects coming from a Judeo-Christian background would be exposed to religious teachings and allow for a concept of God to be developed. It was necessary for both the parents and the children to belong to similar religious affiliations to eliminate any conflict of ideas and beliefs about God in the children.

Access

Subjects were obtained through Dr. Elisabeth McSherry's private patient population receiving care at the Children's Renal Center, Ambulatory Care Clinic at the University of California, San Francisco. Each possible subject meeting the sample criteria and his/her parent(s) were initially contacted by Dr. McSherry to see if they agreed to be contacted by the investigator as a possible participant in the study. If the child and parent(s) agreed, then the family received, by mail, a packet containing: an introductory letter from the investigator, an introductory letter from Dr. McSherry, a copy of the consent forms, and a note informing them that they would be contacted by phone in the near future (see Appendix A for sample forms used).

The investigator then contacted the parent(s) to explain the study further, answer any questions and to learn their decision regarding participation of their child. If

their decision was to participate a date, time, and place was arranged to meet in order to secure a consent and conduct the interview with the child. Demographic information was obtained at the time of the interview.

The interviews were conducted by the researcher, a pediatric nurse experienced and familiar with child development and behavior. Depending on the choice of the parent(s), the interview was conducted in their home or in an interview room at the Children's Renal Center, UCSF Ambulatory Care Clinic. The interview was conducted with the child independent of family members.

Data Collection

Demographic information was procured while the consent was obtained from the parent(s). An explanation of what to expect was reinforced in the child at this time. An open ended, semi-structured interview was conducted after the child viewed a brief demonstration on conservation of space and volume and answered a few questions about what he/she saw. A set of twelve open ended, semi-structured questions were asked during the interview which was either tape recorded or written, depending on the child's preference. The interview, including the demonstration, lasted approximately fifteen to twenty minutes.

First of all, the conservation of space and volume demonstration consisted of pouring water from a tall container into a wider, shallower container. The child was asked if the volume remained the same after pouring the water into

the new container. If the answer was affirmative, the child was asked to explain. If the child attempted or gave some explanation, then he/she was considered in the concrete operational stage. This demonstration provided some means of confirming that the subject was in the concrete operational stage of development.

Next, the interview was conducted in a quiet room. The child was seated near a table facing the interviewer who was also seated. The tape recorder was placed on the table near the child and camouflaged with a book or a bag to prevent distraction. Otherwise, if the interview results were written, the interviewer had a pad and pen on her lap. A series of twelve open-ended, semi-structured questions were asked allowing time for the child to think, comprehend and answer. A time limit of fifteen to twenty minutes was chosen due to the short attention span of this age group.

Interview Guide

The interview guide was developed in consultation with Drs. Elisabeth McSherry, Marilyn Savedra, Eugenia Waechter Randy Byrd and Pastor Billy Martin (see Appendix B for sample interview form). Twelve open-ended, semi-structured questions were developed. Questions emerged from the theoretical and developmental framework. Wording of the questions were concrete, literal and within the child's comprehension. Also, the questions were worded as neutral as possible to prevent any biasing or prompting of answers.

The categories for question included:

1.) a question to elicit a belief or lack of belief in God

2.) acquiring a description of God

3.) how the child learned about God

4.) what the child thought about God and what he could do

5.) whether the child prayed and the content of his/her prayer(s)

6.) whether the child prayed while sick or hospitalized and the content of the prayer(s)

7.) what other things the child did with God besides pray

8.) how God could personally help him/her

The questions were placed in the order of most objective to most personal. This allowed the child to become more at ease with the interview and be less threatened by the personal questions. Similar questions were grouped together to allow for easier comprehension of the questions and a smoother transition of thoughts. An open ended, semi-structured interview was selected to allow the child the freedom to expound on their answers.

Questions that would elicit a belief in God and a description of God were selected in order to obtain and document how these chronically ill children described God. Also, these questions would allow the child to explain in detail any association with God to their health. Questions of how they learned about God would validate sources that would influence their answers. Questions on prayer were included

since (according to the developmental framework) most children used prayer to communicate their thoughts to God. Content of the prayers were elicited in order to document the nature of the prayer, descriptions of God and identify any association of God to their chronic illness. Since play is an important aspect in children's lives, a question about what they do with God besides pray was included. A question on how God could personally help them was asked in order to obtain specific details on how they associated God to their chronic illness.

The interview questions were pilot tested by the investigator on fifteen healthy school age children from an interdenominational church who proclaimed to have an intimate belief and relationship with God. Testing was done during a Sunday school class with consent from the pastor, instructor, and parent(s). These children had no difficulty understanding the questions and responding to them. No discomfort or fatigue was verbalized by the children nor observed by the investigator during the interviews. The interviews took approximately fifteen to twenty minutes depending upon the length of the responses.

Risks and Benefits

The risks were minimized by having Dr. McSherry refer only those patients she felt would be benefited and not harmed by the attention and effort to complete the interview. Fatigue and concern were two risks which were immediately responded to by either stopping the study entirely

or deferring it to another day, at the patient's request. Subjects were informed that there was no right or wrong answer to the questions and that they could choose not to answer any question(s).

Subjects were advised that any identifying information would be kept as confidential as possible and that all tapes and written material would be carefully coded to disguise the identity of the participants. The consent form was attached and the signed consents were stored in locked files.

There was no immediate benefit to the subject other than the satisfaction and joy most children have about sharing what they know and being given the opportunity to discuss his/her spiritual beliefs. Also, the information added to the general body of knowledge about the spiritual dimension of children with chronic renal tubular acidosis. No monetary compensation was offered in this study.

Chapter IV

Results

Out of a convenience sample of fifteen possible subjects, eight children consented to be interviewed. Of the eight subjects interviewed, only seven met the sample criteria and qualified as subjects. The final sample size for the study was seven subjects: six females and one male. Six of the interviews were tape recorded and two were written. One five year old female child expressed a desire to participate and was allowed to be interviewed. Her responses are not included in the overall analysis of the results.

The age range of the subjects were as follows: two were six years old; two were seven years old; two were ten years old; and one was twelve years old. All of the seven children had primary chronic renal tubular acidosis and had been diagnosed for at least two years or more. They all had a history of multiple hospital admissions for treatment and periodic evaluations on clinical visits. All seven children were currently stable on their medical treatment plan for chronic renal tubular acidosis and were not compromised in any way by their illness other than having to take their daily routine medications. These children were considered normally developed for their age by their physician.

Each of the seven children attended school on a regular basis and were in the appropriate grade for their age.

Two of the children attended church affiliated parochial schools where religious instruction was an integral part of their daily school routine. The other five attended public schools.

The religious background of these seven children were as follows: three were Catholic; two were non-denominational protestant Christians; one was Mormon; and one was formerly a non-denominational protestant but was currently attending a Mormon church. Four subjects and their families attended church functions on a weekly basis. The other three subjects' families were no longer active, weekly, church attenders as in the past. These three subjects were currently exposed to church activities through extended family members. (Refer to Table I).

Overview of the Responses

The responses to the space/volume demonstration was age appropriate. All the children from 6 - 12 years of age understood the principles of conservation and reversability. The seven subjects were considered to be in the concrete operational stage of development.

All seven of the subjects stated that they thought there was a God. Their descriptions of God were literal, concrete, physical, and based on past experiences. God was viewed in human form with a beard, mustache, and white robes. They saw him as beautiful, "nice to look at" and with his hands folded in prayer. One child responded from experience stating, "I don't know, I've never seen him."

Table I

Demographic Information

Subject	A	B	C	D	E	F	G
Age in Years	6	6	7	7	10	10	12
Sex	F	F	F	M	F	F	F
Religion	NDC*	C**	C**	C**	M***	NDC*	NDC*
Type of School	pub.	pub.	pri. rel.	pri. rel.	pub.	pub.	pub.

*Non-Denominational Christian

**Catholic

***Mormon

Another child described God as a "spirit" but continued on to use concrete, physical terms to describe God in human form.

All seven children admitted to learning about God from their parents and family. Some children mentioned being taught about God from their teachers, grandmother, friends, or doctor. All seven subjects included other individuals besides their parents from whom they had learned about God. Two subjects stated learning about God from the Bible, books, and television. This may suggest that a child's spiritual development and concept of God is not entirely dependent on parental teaching and influence. Children can be exposed through other sources that can influence their development of the concept of God. Also, these children demonstrated that infrequent exposure or participation in church activities did not necessarily hinder their perception of God or their utilization of their spiritual dimension.

The results showed that all seven children saw God as a person who had some control or power over their lives. The children saw God as an active participant who was always doing things for people such as: praying for people; loving people; "helping everybody with their problems;" teaching people right from wrong; "helping people be brave;" and "making miracles and special things."

Three of the children mentioned God's work through creation. One child mentioned, "He makes the flowers, the

sun and the moon." Another child stated that "He created the earth and can make it rain or snow." God is constantly at work as one child said, "He works with his father; he works in everything." All these children viewed God as a benevolent person: A God who can help people and, "He can help you do anything you want." No mention was made of God as being wrathful, judgmental or punishing. No comment of guilt or blame toward God for their chronic illness was ever made. God was always mentioned as having a positive effect on people's lives. "He works in everything and if you pray to him, he'll kind of change the future." These children seemed to see God as a positive resource during times of need, fear, and trouble. He was described as a person who could effect the change in a positive manner.

All seven children stated that they think about God. Four children thought about God in reference to prayer. Three children stated thinking about God sometime during the day and two children stated thinking about God after reading literature or viewing media releases related to God. Six children stated that they thought about God when they were sick or in the hospital. Only one child denied thinking about God and another one had no response. The one that stated "no," went on to relate that she thought about God when she prayed. So, the negative response could have been stated through some confusion.

All six children viewed God as a resource or help in time of need. Their upper most thoughts were of getting

better, being healed by God, and going home. One subject stated, "I learned that God could heal people and I was thinking maybe he could heal me." Another child stated, "I think about it being nice to have a God because he can help you with things." Two children thought about God as the creator of the world, the universe and man. "If he (God) didn't make my mom and dad, I wouldn't be alive and he created the earth and made man."

God was viewed as a resource that these children utilized during their hospitalization or when they were sick. These results showed that these children do relate God to their illness. This association deals with God as a creator, benefactor of health, healer, and helper. God was described as loving people and having some control over people's lives either in or out of the hospital or during sickness. All seven chronically ill children thought about God sometime during the day or the week. This may suggest that although children may not openly verbalize their thoughts about God, they may think about him and seek him for help and consolation.

That these chronically ill children described God as a positive resource in their lives and associated God with their illness is revealed in their responses to the questions about prayer or talking to God. Their verbal prayers coincided with what they stated God could do. They talked and prayed to God including those times when they were hospitalized or sick.

Six children prayed before meals and at bed time, both at home and in the hospital. One child stated she prayed whenever she was, "...in a jam or sick or need help." Another child stated she tried to talk to God when she had a fever at home. Almost all the children preferred to pray alone with the exception of two who preferred to pray with their parents. Six children stated they prayed alone in the hospital. One child preferred to pray alone because she could say what she wanted, "without holding other people up." Another child stated she prayed alone because, "Nobody else was around."

The content of these children's prayers included specific requests of God or thanks. The prayers were basically egocentric and personal. Five of the children requested good health and healing from sickness for themselves and other children in the hospital. One child stated, "If anybody's sick (I pray) that they'd get well." Another child commented, "I ask him to bless my parents and my family. If anyone's sick, I ask him if he'll heal them or help them." Only one child was unable to verbalize the content of his prayers, but he stated he did pray while in the hospital.

These five children described God as having some control over sickness and having the power to heal. They sought God through prayer in hope of getting well. Also, these five children prayed in the hospital usually for healing, to go home, for family members and pets. Here

again, these children viewed God as a resource. They associated him with their illness and utilized their spiritual dimension through prayer.

Prayer seemed to produce a positive effect in the children when they prayed. They expressed feeling good, happy, fine and okay after praying. One child stated, "If I feel sick, then I feel sort of happy again after I pray." This suggests that prayer to God itself is a resource that the children utilize to cope with their chronic illness or hospitalization.

Six children believed God could help them after they prayed. Only one child commented about having doubts that God could actually hear; "I think he thinks about it. I don't know if he hears me." Two children commented, "He hears me, prays for me and answers my prayers." One child had no responses to this question. This may have been due to an inability to comprehend the question.

Over all, these results on prayer revealed that these chronically ill children described God with the ability to heal sickness, protect loved ones and help them during hospitalization. Prayer was utilized to communicate their thoughts and requests to God for their needs and fears. God was associated with their illness as a resource person who could help them cope with their life both in and out of the hospital. In this context, their spiritual dimension does play a vital role in helping these chronically ill children adjust to their lives.

In response to whether they did other things with God besides pray, four stated that they did, one stated "no" and one stated "yes," but was unable to verbalize a response. Some of the responses were: "I learn about him;" "I talk with him;" "I be with him, share with him and love him, I play hide and seek with him and I see him in everything, and feel good about him." These children's responses to God were very similar to what they would do with their parents or any other significant person in their lives. They demonstrated utilizing this spiritual resource in facets other than prayer.

Each child was asked how they thought God could help them personally. Five were able to respond and one was unable to verbalize a response. Their Judeo-Christian teachings were evident in their comments: "He loves me;" "getting saved and going to heaven;" and "he prays for me." Some children commented on how God could help them personally with their chronic illness. One child stated God helps her, "by helping me get over being sick or being scared and to know that he's with me all the time." Another child specifically stated, "He can help me by making sure nothing happens to my kidney and that I'll take my pills right." On a more personal note, another child stated, "when I don't like my food, he can help me eat it quickly." On the whole, most of the responses carried a tone of security in God because he cared for them, loved them, and helped them.

All the children's responses were in line with their previous descriptions, thoughts, and prayers about God. God still was seen to be able to respond in a benevolent, loving, helpful manner. This further supports the finding that these children associate God in their lives and with their chronic illness. (Refer to Tables II - VII).

Case Studies of the Subjects

As a whole the older subjects had an easier time responding to the questions in the interview than the younger ones. As expected, the younger subjects had a more difficult time expressing their thoughts and would initially respond by pausing to think awhile or state, "I don't know." But with further probing and changing the question to be more concrete, the younger children were better able to respond to the question.

First, the two six year olds responded appropriately to the space/volume demonstration. But, they were easily distracted, which is typical for their age group. One of the six year old girls was highly distracted and complained of fatigue. So, it was decided to terminate the interview early. Out of the four questions she was able to answer, she did confirm a belief in God, described God as a benevolent, attractive person, and presented him as an active God who, "prays for everyone."

The other six year old girl came from a family who no longer actively participated in church activities, but had done so when she was younger. Now her exposure

Table II

Overview of the Responses

Subject	A	B	C	D	E	F	G
Belief in God	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Think About God	Yes	N/C*	Yes	Yes	Yes	Yes	Yes
Think About God in the Hospital	Yes	N/C*	Yes	Yes	Yes	Yes	Yes
Pray to God in the Hospital	Yes	N/C*	Yes	Yes	Yes	Yes	Yes
Prays Alone in the Hospital	Yes	N/C*	Yes	Yes	No	Yes	Yes

*No Comment

Table III

Where Did You Learn About God?

Subject	A	B	C	D	E	F	G
Parents/Siblings		X	X	X	X		X
School		X	X				
Grandparents	X	X			X		
Friends						X	
Books, Bible		X	X				X
Multi-Media			X				
Church	X		X		X		
Health Professional			X				

Table IV

What Can God Do For People?

Subject	A	B	C	D	E	F	G
Love Them			X	X			
Create People					X		
Pray for People	X					X	
Help Them		X	X	X			
Be Our Friend			X	X	X	X	
Answer Prayer		X	X	X			
Do Miracles		X	X	X	X		

Table V

When Do You Think About God?

Subject	A	B	C	D	E	F	G
Night				X	X		X
Day			X	X			X
In Church		X			X		
Multi-Media		X	X				
When Praying	X		X				
Need Help		X	X				X
When Sick	X	X	X	X	X	X	X

Table VI

When You Are Sick, What Do You Think

When You Think About God?

Subject	A	B	C	D	E	F	G
Heal Me		X	X	X			X
Going Home	X						
The Flowers					X		

Table VII

How Can God Help You?

Subject	A	B	C	D	E	F	G
Save Me							
Love Me	X			X			
Help Me		X	X	X	X		
Be Near Me		X					
Pray For Me				X			
Heal Me		X	X	X			X

to religious/spiritual activities was through her grandmother. This exposure amounted to four to five times per year. Despite this infrequent exposure, the child provided a colorful and thorough explanation of her understanding about God.

She described God in human form with "a beard, mustache, and panties." This suggests a recollection of a picture she may have once seen. She viewed God from past teachings, "He go hanged on the crosses. He prays for all things and got us the moon and sun." Also, she presented God from her perspective of the world: "He meets his friends and plays with his friends." Furthermore, she did demonstrate a personal relationship with God in that she prayed to him about personal things such as, "I tell God I love him and I want to go home (from the hospital). I talk about our family, our cows, our ranch, my dog, and my little kitties." She described God as a person who could help her and meet her need for love and security: "He prays to us and talks to us. He can pray to me. He loves me and all my family." Her personal prayers were egocentric and typical of her age group. She did admit to praying alone while in the hospital. She expressed feelings of being sad and mad after praying. But, she also stated feeling good and happy after praying.

Next, the two seven year olds were quite similar to the six year olds in that they also had some difficulty

expressing themselves in their understanding about God. Also, their thoughts about God and their prayer to him were egocentric in nature.

The only male subject was one of the seven year olds. He demonstrated difficulty in expressing himself and often stated, "I forgot," in response to questions. His case was unique because he had foster parents who were very active in church functions. Also, he attended parochial school. He stated learning about God from his foster dad who, "reads me the Bible every night." So, his answers could be very much influenced by his foster parents and school.

When asked about prayer, he admitted to praying in the hospital at night and sometimes during the day. When asked what he prayed about he stated, after much hesitation, "I forgot." This could have been due to forgetting the actual words in set prayers that most Catholics use. Another unique result was that he actually preferred praying with his parents rather than alone. He described God as a benevolent person who could help people. "I think about it being nice to have a God because he can help you with things."

The other seven year old, a female, also went to a parochial school and had a family who was very active in church functions. She was articulate and concrete in some of her responses to the questions. She gave definite details in her descriptions of God up to the actual clothes he wore. "He wasn't black, and he had a dress like a robe

with a little tie." At times she had some difficulty verbalizing her thoughts and said, "Yeah, but I can't think of them."

Like the previous children, she described God as benevolent and a helper of people, who loves people and prays for them. She frequently utilized prayer to God during sickness and hospitalizations. "If I feel sick, then I feel sort of happy again after I pray." She'd seek God for healing by saying, "Can you (God) help me get better or stop vomiting?" She saw God as a positive resource in her life when she said, "If I'm having a hard time, he always helps me a little more. He can make miracles. When I have severe vomiting I ask him to help me, then after that I get better." Her active prayer life and utilization of God as a resource, demonstrates how her spiritual dimension has a definite effect on helping her cope with her chronic illness.

The two ten year old subjects had an easier time expressing themselves, probably due to their increased language abilities and cognitive development. They still tended to be egocentric in their prayers for themselves, their pets and their families. Both described God with physical, human features although one claimed he was a spirit. Both explained God's presence in the creation of the earth and viewed God as a helper who loves people. These children expressed a profound belief that God could help them with their chronic illness and during hospital

stays. One stated, "I learned that God could heal people and I was thinking maybe he could heal me." The other stated, "He can help me by making sure nothing happens to my kidneys and that I'll take my pills right." Like all the previous children, these ten year olds expressed a good or happy feeling after praying. Both children utilized prayer in the hospital and viewed God as a significant resource to call upon in times of need.

One of these ten year olds came from a Christian background whose family was no longer actively participating in their church. Her current exposure to religious/spiritual teachings was through her aunt and uncle's family. This may suggest that early exposure had a definite influence on her spiritual dimension. She stated learning about God not only from her parents, but also from her aunt and uncle. This situation supports the possibility of children developing a spiritual dimension by being exposed through sources other than parents. She still developed strong spiritual beliefs which she calls upon to cope with life's experiences.

Finally, the twelve year old subject had an easier time expressing herself, unlike her younger counterparts. A less concrete description of God is evident in this older age group. She described God in spiritual form, but would revert back to concrete and physical features to further describe God. She also described God as a benevolent person who could help people and effect positive change in their lives. Although she admitted to

praying to God during a jam or when she needed help, she also prayed for other sick people she'd see in the hospital. Less egocentric prayers now emerge in this older age group. She sees beyond herself and views God as helping people with their illnesses. "I hope everybody gets better."

Another area where she utilized God was when she was scared. She prayed to God for help during frightening experiences and experienced comfort. "God I need help. What should I do? Then later the fear goes away." She expressed a feeling of his presence in her life, "In ways I know he's there because I see him all around me . . . . I see him in everything, everywhere. I feel good about him." This subject expressed her spiritual dimension and how she utilizes it in her life. She actually viewed God as a resource to be called upon during times of fear and need. She described God as both healer and helper during her illness. Prayer seemed to play a significant role in her ability to cope with life. Thus, she demonstrated an association of God to her illness in a positive way.

Chapter V

Discussion of Results

Summary

The findings of this study document how school age children with chronic renal tubular acidosis during a period of relative wellness describe God and how they associate God to their illness. These children in concrete terms described God as a person with human form. They further characterized God as good, kind, and loving toward people. God was described as the creator and someone who prayed for people, helped people, comforted people and healed people.

Secondly, these children viewed God as positively associated with their illness. God was seen as a significant resource to call upon in time of need. They believed God could help improve their health and be a supportive figure during hospitalization and illness. Furthermore, these children described having a relationship with God that helped them comply with medical treatment for their illness. This involved being able to ask God for help and feeling secure that God was near at hand.

Finally, this study revealed that in these chronically ill children, their spiritual dimension played an important role in their lives. These subjects expressed a relationship with God by: prayers to God, benevolent thoughts about God, answered prayers from God, a sense

of assistance from God in stressful situations and viewing God as their creator.

The results showed that their spiritual dimension helped them adjust and cope with conditions placed on them by their chronic illness and life in general. These children thought of God as a support during illness and hospitalization. Also, these children utilized prayer as a means to communicate with God both privately or with others, in and out of the hospital and during acute episodes of illness.

Limitations

The major limitation of this study was the small sample size in a restricted illness category. This limits the generalizability of the findings to the sample population of children chronically ill with renal tubular acidosis. It would be valuable to collect data from children with other chronic and acute illnesses, healthy children, children from other religious affiliations and children with no religious affiliation or limited religious exposure. It was not feasible to remedy the limitations on sample size or to include healthy children, children from other religious backgrounds or with other illnesses.

Another limitation was the short attention span of this age group which restricted the time of the interview. Little time could be spent on any in-depth questioning in reference to the set interview questions.

The interview guide posed no real problem during this study. This interview guide was reviewed by the thesis committee and was derived from past studies which demonstrated face and content validity. But, reliability of the interview guide has not been established.

Comparison of Results with Past Studies and Developmental Theory

Children's understanding and cognition of the spiritual realm is dependent on their level of thinking (Goldman, 1964; Piaget, 1929). Therefore, children in the concrete operational stage of development will describe and explain their experiences in physical, literal, concrete terms. In this study, the children described God in human terms. They described God as a healer, creator, a person with power to control the outcome of their lives and a loving person who could help people in times of need. The data confirmed results from past studies that children at this age see God on an anthropomorphic level (Piaget, 1929). As in Goldman's (1964) studies, God was described with magical powers to heal. Contrary to Brazelton's (1964) theory that children may view their illness as punishment from God, all seven children viewed God as a benevolent person who had the ability to restore their health. They looked to God as a positive resource in their lives.

Children's beliefs and ideas about God tend to be influenced and colored by their parents, home and church

school (Goldman, 1964). The children admitted to learning about God from parents, teachers, friends and/or doctor. Some of their responses about what God does or what they pray and think could have been attributed to their past teachings. For instance, "He created the earth, he created people and sometimes if they die he can make them alive again." Also, "He works with his father in everything. He makes miracles and prays." These responses are reflective of Biblical teachings. The findings in this study confirm the findings of past studies that show children often respond to religious or spiritual related questions as they were taught by their parents and teachers (Piaget, 1929; Elkind, 1974; Goldman, 1964).

Another characteristic of this age level is that their religious ideas and explanations are concrete, physical, and literal. They draw upon everyday experiences and concepts in life to understand and explain God. This concept was well demonstrated in this study. In response to what God does, one child stated, "He meets his friends and plays with his friend." Since play is important to the younger ages of the concrete operational stage, these children may very well include play in their comments. These findings agree with the past studies by Piaget (1929) on the characteristics of the younger children in the concrete operational stage.

Prayer at the concrete operational stage is still egocentric. Prayer is understood as talking with God as well as asking for things (Elkind, 1974). In this study, prayers centered around the children's own well being, their family, pets and other children in the hospital. The twelve year old stated, "I hope everybody gets better. I hope the world will straighten up its act." This response supported Goldman's (1964) findings that the older age group was less egocentric and more general in their prayers. Goldman (1964) also stated that some satisfaction in prayer begins at nine to thirteen years, but all seven children in this study expressed having positive feelings after praying, regardless of their age.

Finally, this study compared positively to the past adult studies on how hospitalized adults utilize their spiritual dimension (Crooge and Levine, 1972; Florell, 1973). Like the adult studies of Crooge and Levine (1972) and Florell (1973) the children utilized their spiritual dimension as a resource during hospitalization and sickness. Both the children in this study and the adults in the past studies (Crooge and Levine, 1972; Florell, 1973) thought of God as a support during illness and hospitalization. They prayed to God, thought of God as a healer and friend, and sought God's help in times of stress. Both these chronically ill children and adults associated God to their illness in

a positive manner and demonstrated that their spiritual dimension played a role in helping them cope.

Discussion of the Descriptions

The findings of this study are important in that they support the need to consider the spiritual as well as the physical dimension of children. This study has shown that school age children of this study do associate God with their illness by utilizing their spiritual dimension as a resource in adjusting to experiences placed on them by their condition. By analyzing the comments made by these children, most of their descriptions about their spiritual dimension were based on Biblical concepts. Results from the data show that most of these children described God in terms of being merciful, loving, caring, having the power to heal, create life, communicate with people through answered prayers, being present in their lives and assisting them during stressful times. These ideas are addressed in the Bible. It seems possible that these children derived those beliefs from Biblical concepts taught them by family members, teachers, and religious leaders.

In Judeo-Christian teachings, the Bible speaks of God as: being loving and benevolent (Psalm 91, 103:8); having the power to heal (Matthew 4:23, 9:35); having the power to do miracles (Jeremiah 32:27); being able to assist and help people (Matthew 11:28; Isaiah 43:2); desiring to communicate with people (Revelation 3:16;

Jeremiah 29:11-14); and having a special concern for children (Matthew 18:5; Luke 18:15-17). Being exposed to these Biblical teachings could have influenced the development of these children's spiritual dimension and verbal descriptions of God.

Though the sample was small, a trend among the subjects seemed to show they had positive feelings toward God. Most of them provided positive remarks in relation to God as a helper, healer, friend and one who loved them. Most would converse in prayer to God and talked freely of some type of relationship with God in terms of thinking about Him, believing in His creative powers and actively seeking Him as a resource during times of stress. They also seemed to rely upon the spiritual support of others. Some subjects expressed being supported by family members and others were helped by prayers, bed time rituals and through school. Possibly, some subjects may have a need for support from family members and others who can assist them in their spiritual dimension. Children's support systems for their spiritual dimension has yet to be explored, but these support systems may include health care providers especially during hospitalization, medical treatment and stressful procedures. This support may assist the children to utilize their spiritual dimension to cope with experiences and have improved compliance to medical care for their illness.

Some children stated their parents prayed with them, the Bible was read to them, they attended private religious

affiliated schools and went to church services. There is some indication that Biblical teachings and spiritual support from others helped enhance the children's spiritual dimensions. Therefore, the Bible, family and others are probably valuable resources and probably can assist to maintain and encourage school age children to utilize their spiritual dimension to cope with illness and stressful situations.

Implications for Nursing

The results of this study have significance for anyone working with children, especially nursing personnel. Nurses need to recognize that children do have a spiritual dimension along with the physical and psychosocial dimensions. They need to deal with the chronically ill child as a whole being whose various dimensions are affected by the illness process.

First of all, the children in this study were able to answer the questions about their spiritual dimension without difficulty. This interview guide's questions may be a valuable tool for nurses to use to assess the chronically ill child's spiritual dimension. None of the children in the study seemed in any way distressed or offended by the questions. The open ended, semi-structured format seemed to enhance verbalization and thoughts about the subject's spiritual dimension. This interview guide could be a guide to initiating conversation and assessing the spiritual needs of a hospitalized school

age child, or a child about to undergo a stressful experience.

In addition, this study supports current nursing literature on the spiritual dimension of man. Nursing literature contains care plans and assessment strategies for dealing with the spiritual dimension (Betz, 1981; Stoll, 1979; Israel, 1977; Fish and Shelly, 1978). Yet no previous studies document how ill or hospitalized children describe God, if they in fact associate God with their illness and if so, how they associate God to their illness. This study in a small way, addresses this lack.

Children do have a spiritual dimension that is an integral part of their lives. Some of them utilize their spiritual dimension as a resource to cope with illness and hospitalization. Nurses need to recognize this spiritual dimension in children and then assess this as a possible resource for coping with illness and stressful situations. Health professionals in general need to recognize man as a spiritual, psychosocial and physical being at every age and that the total assessment of their clients and interventions need to include all three components. A more comprehensive wholistic health care approach could in fact improve patient compliance to health care and maintain a better standard of health in the community.

Future Research

The main direction suggested by this study is to increase the sample size and expand the study population to

include other age groups, children with other chronic or acute illnesses, healthy children, children from other religious and children from non-religious backgrounds or those with limited religious exposure. It would be valuable to compare the results from future studies and this study with healthy children's religious perceptions.

Secondly, this study should be replicated with larger numbers of cases to aid the reliability assessment of the interview guide. The results of similar studies could then be compared to the results of this study.

Future studies also should be planned to categorize associations of God to illness in children. This could possibly be done by developing a tool, similar to the interview guide used in this study including multiple choice questions. Further, studies could test for the presence of spiritual needs specific to chronically ill children. Also, longitudinal studies on how the spiritual dimension develops, changes, and is utilized throughout the child's growing process into adulthood would be valuable especially in cases concerning chronic illness or acute illnesses.

It was unexpected that none of these children in the study attributed any negative causalities of their illness to God. God was often mentioned as a healer and helper but, never as causing their illness. God was given credit for creating life but, not destroying it. It would be interesting to test for this as a possible belief in future

studies with children. The present interview could be expanded to include questions that would address this issue.

After future studies have defined some spiritual needs of chronic or acutely ill children, various interventions and the quality of specific spiritual care given by health professionals could be assessed. Future studies could be undertaken to evaluate the effects of specific spiritual care given by health professionals geared toward improving well-behavior and compliance to health care by chronically ill or acutely ill children. Such studies would be important in assessing any improvement in compliance, coping abilities and adjustment to illness in chronically ill, acutely ill and hospitalized children where spiritual care has been assessed and provided by health professionals.

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Appendix A

Letters of Introduction

Dear_____,

Melinda Sarmiento is an R.N. and a graduate student in the Masters program at the UCSF School of Nursing. She is conducting a study concerning special spiritual needs of children with renal tubular acidosis. She has informed me on the details of this study and I have given her permission to seek possible subjects for her study from among my patients receiving care in the Pediatric Renal Metabolic Clinic at UCSF's Ambulatory Care Clinic.

You and your child's participation in this study is entirely voluntary. Your decision to participate or not will in no way jeopardize the care your child receives at UCSF Medical Center.

Sincerely,

Elizabeth McShane MD

EM/ms

Hello,

I am Melinda Sarmiento, an R.N. and graduate student at UCSF's School of Nursing. I will be conducting a study to gain information about the spiritual dimension in children with renal tubular acidosis. This information may help health professionals recognize these children's needs in the spiritual dimension and learn to provide better care in this area.

Enclosed you will find a letter from your physician stating that she has given me permission to see you if you would like to participate in this study.

In addition, you will find a copy of the consent form that explains this study. You may want to read and discuss this with your family. In the near future, I will be contacting you by phone or during a clinic visit in order to explain the study further, answer any questions, and see if you would like your child to participate in this study. If so, we can set up a date, time and place to meet at that time.

If you have any questions, you may call me at (415) 681-0412.

Thank you for your time and consideration.

Sincerely,

Melinda Sarmiento

MS/vla

Appendix B

Consent Forms

University of California, San Francisco
CONSENT TO BE A RESEARCH SUBJECT

Spiritual Dimension in Chronically Ill Children

A) Melinda Sarmiento, R.N., BSN, is a graduate student at the UCSF School of Nursing, in collaboration with my child's nephrologist, Dr. Elisabeth McSherry, is doing a study to gain information about the spiritual dimension of children from 6-12 years who have chronic renal tubular acidosis. Because my child is within the age range and has renal tubular acidosis, he/she has been invited to participate in this study.

B) If I agree to have my child participate in the study, the following will occur:

1) Melinda Sarmiento will interview my child at the clinic or our home on an agreed date and time at our convenience.

2) First, my child will watch a brief demonstration of water being poured from one container into another, followed by some questions on what he/she saw. Then, several questions will be asked about my child's spiritual beliefs and how he/she associates those beliefs to his/her chronic illness. The conversation will be tape recorded or written depending on our preference. The interview should require 15 minutes of my child's time with an additional option of 5 more minutes if my child requires more time to respond.

C) All information will be kept as confidential as possible and every precaution will be taken to safeguard my child's name, thoughts, and feelings as a participant.

D) Participation in this study may mean some risks and discomforts:

1) My child may experience a loss of privacy or concern due to the nature of the interview questions. If so, this study may be stopped in entirety or my child may elect to respond only to those questions he/she sees fit.

2) My child may become fatigued by the length of the interview procedure. If so, this study may be stopped in entirety or deferred to another day at his/her request.

E) This study will result in no direct benefit to me or my child, other than the satisfaction of being given an opportunity to discuss his/her spiritual beliefs. Also, the information may add to the general body of knowledge about the spiritual dimension of children with chronic renal tubular acidosis.

F) Melinda Sarmiento has clearly explained the study to me. For further questions, I may contact her at (415) 681-0412 and/or Dr. McSherry at (415) 666-4242. I have been given a copy of this consent form and the Experimental Subject's Bill of Rights to keep.

G) Participation in research is voluntary. I may refuse to participate in this study and may withdraw at any time without jeopardy to the treatment my family and child will receive at UCSF Medical Center. I just have to say so.

_____ _____

Date Parent Signature

Subject is a minor (age____)

University of California, San Francisco
Assent to be a Research Subject

Spiritual Dimension in Chronically Ill Children

Melinda Sarmiento (a nurse) will be asking you some questions to learn whether children with renal tubular acidosis think about God and, if so, what they think about.

You have been picked to help in this study. Your Parents know about this study. If you decide to take part, you will have to answer some questions asked by Melinda Sarmiento. First, she will pour a glass of water into another glass and ask you about what you saw. Then, she will ask you some other questions to see if you believe in God and, if so, what you think about God. You can say whatever you want. There is no right or wrong answer -- any answer is correct. You will not be graded in any way.

You will have a choice to have this conversation tape recorded or written and it should take 15 minutes of your time. Melinda will keep your name and identity out of this study and private as much as possible.

You do not have to answer any question(s) if you do not want to or feel like it. If you decide to answer the questions, you may enjoy sharing your thoughts.

If you want to take part in this study, please sign your name below.

_____ _____

Date Subject's Signature

EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

1) To be told what the study is trying to find out,

2) To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice,

3) To be told about the frequent and/or important risks, side effects or discomforts of the things that will happen to me for research purposes,

4) To be told if I can expect any benefit from participating and, if so, what the benefit might be,

5) To be told the other choices I have and how they may be better or worse than being in the study,

6) To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study,

7) To be told what sort of medical treatment is available if any complications arise,

8) To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study.

9) To receive a copy of the signed and dated consent form,

10) To be free of pressure when considering whether I wish to agree to be in the study.

If I have other questions I should ask the researcher or the research assistant. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling: (415) 666-1814 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing to the Committee on Human Research, University of California, San Francisco, CA 94143.

Call X1814 for information on translations.

Appendix C

Interview Guide

INTERVIEW GUIDE

Demonstration: A half-filled tall glass of water will be poured into a wider, shallower, empty glass. A school age child who is definitely in concrete operational thought should be able to understand the conservation of space and volume. To verify the school age child's cognitive developmental level, the following questions will be asked after the child has watched this demonstration. This demonstration should take three minutes.

Questions: 1) Is the amount of water in the second glass the same as the amount of water in the first glass?

2) Why?

Interview

The interviewer will interview the subject independent of family members. The interview should take about twelve minutes.

Explanation and Questions

I will be asking you some questions about what you think about God. Any answer is correct. You will not be graded. Answer as best you can in your own words.

1) Do you think there is a God?

2) Describe for me what you think God looks like.

3) Where did you learn about God? Or who taught you about God?

4) What does God do? Or what can God do?

5) What does God do for people?

6) Do you think about God? If yes, when?

7) Do you think about God when you are sick?

8) Do you think about God when you are in the hospital? If yes, what do you think about?

9) Do you talk with God? Or do you pray to God? If yes:

   a) When (morning, evening, before meals)?

   b) Do you talk/pray to God alone (family, parents, others)?

   c) What do you say to God? Or what do you talk/pray about?

   d) How do you feel afterwards?

   e) What do you think God does after you pray?

10) Do you talk to God when you are sick? Or do you talk to God when you are in the hospital? If no, why? If yes:

   a) When (morning, evening, before meals)?

   b) Do you talk/pray alone (family, parents, others)?

   c) What do you say? Or what do you talk/pray about?

   d) How do you feel afterwards?

   e) What do you think God does for you after you pray?

11) Do you do other things with God besides pray?

12) How do you think God can help you?

Interview will be tape recorded or written depending upon the subject's choice. The entire interview should require fifteen to twenty minutes depending upon the length of the subject's responses.