

PARENTAL PERCEPTIONS REGARDING HEALTH CARE
INFORMATION AND SUPPORT FOR FAMILIES
ADOPTING INTERNATIONALLY

by

Marie Annette Sills Mitchell

A project submitted in partial fulfillment
of the requirements for the degree

of

Master of Nursing

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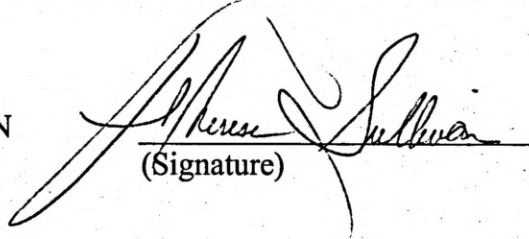
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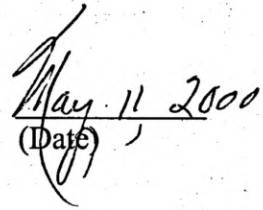
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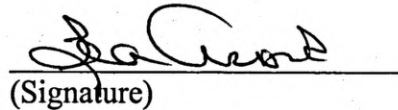
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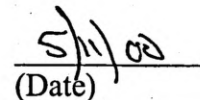

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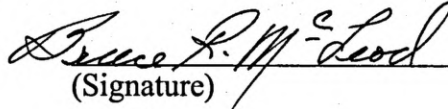
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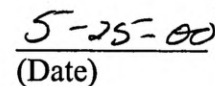

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ABSTRACT

The health picture of internationally-adopted children has changed as the number of adoptions and the number of source countries for them have increased. In the past, the majority of children were adopted from Korean foster care homes, from a country where there is a high standard of living and access to quality health care. Between 1995 and 1999, either China or Russia led in international numbers. The children from these countries are raised in orphanages with high child to staff ratios and incomplete, often nonexistent, health care.

Studies of today's institutionalized children show similar findings to studies done in the early 1900s which indicated that orphanage life has deleterious effects on the lives of children. Additionally, adoption agencies receive incomplete information about the health of adoptable children and health care providers in the United States are often unprepared to meet the needs of adopting families.

The purpose of this study was to explore parental perceptions, attitudes, and feelings about the kinds of health information parents were provided, and what was most useful to them at different time periods in the adoption process. Parents who had adopted internationally in the past ten years served as the target group in this qualitative study that used focus group methodology. Kohnke's model of advocacy was used as the conceptual framework.

Results indicated that parents were knowledgeable about adoption in general and were aware that health and social information provided in the adoption process would be incomplete or unavailable. Various health care providers and specialists were utilized during the process, although most were contacted after the child was in the adoptive home.

Conclusions were that parents received incomplete health information in all phases of the adoption process, but that it was enough upon which to make a decision to adopt or not. Adoption agencies and other parents were important sources for information, although a variety of other sources were also used. An unexpected finding was that parents reported bonding to the child referral photograph and could not be deterred from accepting the referral, even when the child received a negative preadoption health appraisal.

CHAPTER 1

INTRODUCTION

The number of children adopted internationally by United States citizens has increased dramatically in the past 10 years. From 1990 to 1999 the adoption rate more than doubled from 7,093 to 16,369, and the number of countries involved in international adoption also increased (U. S. Immigration & Naturalization, 1999). With the exception of 2,594 adoptees from Romania in 1991, the majority of internationally-adopted children up until 1995 came from Korea. Between 1995 and 1999 either China or Russia consistently led international adoptions with Korea ranking third (Figure 1, Appendix A). In 1999, China and Russia together comprised 52% of all international adoptions, with Korea adding another 12% (U. S. Immigration & Naturalization, 1999).

The shift in sources of adopted children dramatically changed the overall health picture of internationally-adopted children. Korean orphans come from foster-care homes in a country where there is a high standard of living and access to appropriate health care with excellent medical record documentation. Most other adoptees come from orphanage settings in developing countries where the standard of living is poor. Health care is often unavailable or not comprehensive and medical records are scant, unavailable, or unreliable (Johnson, 1997; Jenista, 1993).

Children from orphanages present different health concerns than those routinely seen in a typical United States pediatric practice. Health care providers to whom prospective parents turn for assessments of a child being considered for adoption may not be aware of issues relevant to today's adoptees and the children may not receive health

care that addresses these issues once in the United States (Mitchell & Jenista, 1997).

Additionally, parents may not receive appropriate information, resources, or referrals that promote health for their children.

Project Purpose

The purpose of this project was to (a) explore parental perceptions, attitudes, and feelings about the preparation and type of health care information they received during the international adoption process and post adoption and (b) parent assessments of the usefulness of this information in preparing them to identify health care needs and access appropriate resources. The information obtained from this project may be used to direct prospective adoptive parents to health care information, resources, and referrals during all phases of the adoption process. With appropriate information and support, parents can best advocate for their child.

Background and Significance

The number of children adopted internationally continues to rise each year. With the increase in the number of adoptees and countries involved have come new, unexpected health concerns. Most of these are a result of institutionalized living. The negative effects of institutionalization were initially identified by Dr. Henry Dwight Chapin (1908, 1915) and later by others (Bakwin, 1949; Bowlby, 1966; Goldfarb, 1945). Some studies of adoptees from today's orphanages (Hostetter, Iverson, Thomas, McKenzie, Dole, & Johnson, 1991; Jenista, 1993) reveal similar findings and reinforce the idea that orphanage life often has deleterious effects for children.

These studies also indicate that internationally-adopted children often enter the United States with a myriad of treatable medical conditions in addition to some negative effects related to orphanage living such as growth and developmental delays. Although some of the effects seem to be short term, others (e.g., attachment problems) are thought to be long lasting. The negative effects are seen so frequently, however, that Johnson (1997) warns that children who have been adopted from orphanages are "... a high-risk group by any standard" (p. 27).

Once in the United States, internationally-adopted children do not always receive appropriate health care assessments or referrals. This may be due to the health care provider's inexperience with the health issues of internationally-adopted children, false reassurance of a child's health based on physical appearance, or assumptions that the visa medical examination prior to entering the United States was reliable (Mitchell & Jenista, 1997). Diagnoses are often missed (Hostetter et al., 1991). The American Academy of Pediatrics' Red Book (Committee on Infectious Diseases, 1997) recommends specific post adoption health assessment screenings. However, this has had very little impact on post adoption health assessments (J. Jenista, personal communication, August 13, 1998).

The types and amounts of health information being provided to families before adoption, including effects of institutionalization, have increased over the past ten years (Jenista, 1999d) and prospective parents are increasingly being advised to seek the advice of a health care provider when adopting (Jenista, 1999a). Some families will access international health experts for this initial exam, but most families will utilize their primary care provider for the initial assessment, even though the provider may not be knowledgeable about the issues of international adoption (Jenista, 1999b). Jenista

believes these providers can still provide an initial assessment because it “is not complicated and most pediatric experts already have the necessary skills [although] they may need a little prompting to make sure all important issues are addressed . . . ” (p. 2).

In addition, the quality of information provided by adoption agencies varies. Many times information about a particular child is too sketchy to provide a realistic health picture of that child. Medical records are often scant, old, and unreliable (Mitchell & Jenista, 1997). Sometimes, no records are provided, and the agency relies on verbal reports of a child’s condition and welfare from orphanage personnel or adoption facilitators who may ultimately benefit financially from the adoption (Jenista, 1999d). Video tapes, when provided, are of varying usefulness in assessing health risks (Mitchell, 2000).

Additionally, health information provided to adoption agencies is often incomplete, if available at all. Not surprising, some adoptive parents later discover the child they adopted has medical conditions or negative effects of orphanage life for which they were not prepared. Some families have sought legal recourse, alleging they have received less than full disclosure of potential and existing health problems (Deane, 1997).

Adopting from a country outside North America often means accepting a child with an unknown medical past. Understandably, this can cause anxieties for adoptive parents. Unfortunately, there is no single, comprehensive source of health information for parents. Information and resources families have accessed were often discovered through their own efforts and to a large degree, luck. In the end it is parental persistence that provides the foundation for the ability serve as an advocate for the child they adopt.

Knowing what information and community resources have been most helpful to adoptive parents is important in determining how to best meet families' needs for health information and education pre and postadoption. Although adoption agencies and health care providers often share the responsibilities for educating prospective parents about potential health issues, it is the adopted child who will benefit from the information the parents access.

Project Objectives

The objectives of this project were to: (1) explore the kinds of health information and available resources adoptive parents received prior to, during, and after the adoption process; (2) determine from the information and resources they received which were most helpful and why; (3) ascertain parents' perceptions about what health information was most important to know and access at different stages of the adoption process; and (4) identify specific resources that provided support to adopting families.

Prestudy Assumptions

Prior to conducting this study, several assumptions were made by this researcher, which included:

- (1) Parents had impressions about adoption in general prior to receiving information as a part of the adoption process.
- (2) Adopting parents desire to be fully informed about expectations in the adoption process.

(3) Health care providers, including specialists, are a main source of information and support for adopting families.

(4) Parents will receive health care from their usual health care provider for their internationally-adopted child.

CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Literature ReviewThe History of Adoption in the United States

Adoption is a “method of establishing by law the social relationship of parent and child between individuals who are not each other’s biologic parent or child” (Carp, 1998, p. 3). The concept is not new. The Bible identifies the Hebrew, Moses, as being adopted by an Egyptian Pharaoh in the Book of Exodus. Adoption practices, motives for adopting, and attitudes about adoption have changed in various ways since that time.

Throughout the course of American history, children were often removed from their biologic families because they were poor, neglected, abused, or orphaned. Many were cared for in private orphanages (Carp, 1998). Between 1853 and 1929, “orphan trains” relocated more than 200,000 children from the East Coast to other states where many of them were adopted by the families who received them (Holt, 1992). Later, the public attitude shifted to the belief that staying with one’s blood relatives was superior to being adopted. As a result, even when it may have been in the child’s best interests, social workers began to make efforts not to disrupt families. Thus, fewer children were available for adoption (Carp, 1998).

The twentieth century saw the advent of private adoption agencies. Placing children in adoptive homes became a business (Carp, 1998). After World War II the adoption rate increased. Between 1937 and 1945 the rate tripled, doubling again by

1955 (Carp, 1998). By the 1950s reliable and accessible forms of birth control, the legalization of abortion, and society's more accepting attitude toward single parenthood decreased the number of healthy, white, North American babies available for adoption (Carp, 1998). Additionally, in response to the National Association of Black Social Workers' objections to placing American black children in white families in the 1970s, statutes were passed that would only consider black families to adopt these children. This movement decreased the number of American children available to be adopted by white American families. As a result, many families increasingly turned to intercountry adoption (Register, 1991).

The History of Intercountry Adoptions by U.S. Citizens

Between 1946 and 1953 United States citizens adopted 5,814 orphaned children who were brought to America post World War II from Greece, Germany, and Japan. Again, between 1953 and 1962 there was a surge in the number of children adopted internationally as a consequence of the Korean War. Between 1966 and 1976 there were 32,000 adoptions from Asia, primarily from the Republic of Korea (Carp, 1998). By 1999 the former Soviet Republics and China led in international adoptions numbers. In that year 16,369 children were adopted from countries outside the United States (U. S. Immigration & Naturalization, 1999).

Children have traditionally been available for adoption from other countries as a result of being orphaned due to war. In addition, some children are legally relinquished by their biologic parents and some are physically abandoned. Poverty and homelessness, the stigma of bearing a child without being married, the inability to care for a child with

handicapping conditions, child abuse and neglect, and poor social conditions are also reasons why children are available for adoption (Register, 1991).

Countries do not react favorably to being viewed as chief sources for internationally-adoptable children. The numbers of children available for intercountry adoption from Korea declined after the 1988 Seoul Olympics when international television broadcasted a feature story on the numbers of Korean children available for adoption (Jenista, 1993). In 1991 the number of adoptions from Romania peaked. However, in 1992 Romania tightly curtailed adoptions due to negative publicity (Sweet & Bryan, 1996).

The Intercountry Adoption Process

The adoption process can impact the ways in which adopters view themselves as parents as well as how they view their family formed through adoption (Melina, 1998). The process begins before the actual adoption takes place with a lengthy, detailed assessment of prospective adoptive parents' ability to parent and provide for a child. In addition to the usual preadoption classes that most agencies provide or recommend, a "homestudy" process is a requirement for adoption. In this segment of the adoption process, a social worker is assigned to assess the prospective parents for their ability and preparedness to parent (Hicks, 1993). The preferred term for homestudy is "parent preparation" because it is intended to also serve as an educational tool to prepare prospective parents for adoption, rather than just as an assessment tool (Johnston, 1994).

Individuals and couples wishing to adopt internationally can do so independently or through a private adoption agency. A minority of adoptions are facilitated by a United

States attorney or by contacts within the country from where a child is being adopted. When adoptions are facilitated by United States attorneys or in-country contacts are used, the adopting families may still need to undergo the homestudy [parent preparation] process in the United States. An attorney in the country where the adoption takes place can then complete the legal paperwork for the adoption. Most adopting families, however, use placement agencies (Sweet & Bryan, 1996).

Private adoption laws vary from state to state, and agencies also differ in their requirements, services, and fees. Despite differences, all agencies are required to meet state laws, United States immigration laws and requirements, and legal requirements for the country from which a child is adopted (Adamec, 1998).

A Profile of Adopting Parents

The typical American adoptive parents, whether adopting domestically or internationally, are married, without children, and may have experienced infertility. Although those adopting domestically are usually in their mid-to-late 30s, those adopting internationally are often older. Both parents usually work outside the home with middle incomes. White families adopting internationally often adopt transracially, whereas black families tend to adopt within their race (Adamec, 1998).

Differences Between Adoptive and Biologic Families

The parenting role is the same for adoptive and biologic families, however, adoptive parents' role adaptation comes about differently. Historically, society's views on adoption as "second best" to having a child biologically, have impacted on this role

(Adamec, 1998). Although many adoptive families may agree that adoption is a second choice, it is often the best choice for them. This does not mean that a family formed through adoption is inferior to a family formed biologically, but it is different. The differences lie in the adoptive parents themselves, the children they adopt, and how society views both them and the concept of adoption. Knowing how adoptive parents differ from biologic parents is important to understanding how they approach parenting.

Lois Melina (1998), an adoptive mother and author of books about adoption, describes adoptive parents as:

... intensely concerned, deeply committed parents, who believe strongly that they can make a difference in their children's lives. ... I think there's also strong evidence that infertility, as well as the adoption process and the reaction of people outside the family to the idea of adopting, contribute to parental attitudes. Adoptive parents bring their attitudes to every aspect of their role. (p. 132)

For the adoptive parent, feeling entitled to parent a child that was born to someone else is an additional issue. In her book, Launching a Baby's Adoption, Johnston (1997) uses clinical social worker, university professor, and adoptive parent Jerome Smith's (cited in Johnston, 1997) definition to further expand the concept of entitlement.

Entitlement ... is a multi-step process which includes recognizing and accepting the differences which are inherent in adoption, learning to handle reflections of the societal view of adoption as a second best alternative ... and recognizing and dealing with feelings about the circumstances that brought each member of the family to adoption in the first place. (p. 35)

The title of Register's (1991) book, Are Those Kids Yours? reflects the perception of others that in order to be a "real" parent one must be biologically related. Families who have adopted transculturally or interracially, where the children do not physically resemble their parents, may especially feel that others notice the difference and question their right to parent (Register, 1991).

Both biologic and adoptive parents have fears about the health of their children. Some expecting parents fear miscarriage and the loss that will ensue; however, the risk for miscarriage declines substantially after the first trimester (Ratcliffe, Byrd, & Sakornbut, 1996). For some adopting parents, however, the fear that an adoption may “fall through” may persist until the child is actually in the adoptive home and beyond. For biologic parents there is a pregnancy which entails physical changes that are noticeable to others. Prospective adoptive parents do not look different because they are expecting a child, and the waiting time after referral of a child is often unpredictable. The waiting period is often one of apprehension and uncertainty (Jewett, 1978) and so many prospective adopters do not prepare for the child’s arrival (Melina, 1998).

In addition, unlike the biologic mother who has some control over diet and other exposures to her unborn baby, adoptive parents have no control over the birth mother’s prenatal care and may have no knowledge of her health problems or exposures (Adamec, 1998). The biologic mother does not choose her baby, but an adoptive mother may feel that because she has agreed to accept the referral of a specific child that she is responsible if the child has unexpected problems (Adamec, 1998). Prospective adoptive parents also do not have a nine month time frame in which they can expect to become parents. The period of time between application for adoption and actual placement in the home varies among adoptions (Lancaster, 1994).

Adoptive parents undergo expenses related to adoption that biologic parents do not. Tax credits for adoption became available in 1997, and some employers also offer adoption benefits. These have been a financial help to some adoptive parents, however adoption fees and expenses can still range from \$15,000 to \$20,000 or more (Adamec,

1998). Finally, like many biologic parents, many adoptive parents are first-time parents. However, for the family who adopts internationally, the child is rarely a newborn (Lancaster, 1994).

Care of the Orphaned Child: What History Tells Us

In 1908 pediatrician Henry Dwight Chapin outlined a plan to remedy the ill effects of institutionalization by having children cared for in private homes in the countryside. His negative impression of institutionalization was that "... collecting many little children under one roof is not good for them, no matter how well managed the institution" (p. 491) and that [children] "never do well in institutions, no matter how carefully and scientifically they are fed" (p. 495). In 1914 Chapin addressed the Fifth Annual Meeting of the American Association for Study and Prevention of Infant Mortality in Boston on the issue of institutionalizing infants. He stated: "Our experience leads us to the conclusion that a large segregation of babies under one roof is fatal to their well being and health" (Chapin, 1915, p. 2). He cited the mortality rate among infants in the institutions studied as 2 to 3 times higher than the general population (Chapin, 1915). The negative effects of institutionalization were later noted by others.

Goldfarb (1945) compared institutionalized children to those raised in foster-care homes and discovered that institutionalized children did not fare as well in the areas of intellect, concept formation (the ability to form abstract relationships between various stimuli), and expression of concept comprehension (such as time and space and learning rhymes and songs). They also did not exhibit normal inhibitory patterns of behavior, displaying hyperactivity and disorganization instead. Indiscriminate friendliness was

exhibited and sometimes manifested as demanding behaviors or constant needs for affection which made attachments to others difficult. The institutionalized children also did not exhibit usual anxieties after displays of hostile, aggressive, or cruel behaviors. Finally, the institutionalized children were socially immature as adolescents compared to adolescents who had been raised in foster-care settings.

The research of orphanage infants by Spitz (1945) identified developmental delay, susceptibility to illness with high mortality rates, and unusual reactions to strangers (ranging from extreme friendliness to “anxious avoidance of inanimate objects” (p. 72), to screaming that continued indefinitely). Brodbeck and Irwin (1946) evaluated the speech behaviors of institutionalized children. They discovered that orphanage infants at all ages studied (birth to 6 months) did not make as many sounds as infants raised in families.

Harry Bakwin’s (1949) studies of institutionalized children revealed that infants less than six months old who lived in orphanages were listless, emaciated, quiet, and relatively immobile with unresponsiveness to social interaction and poor sleep patterns. They also failed to gain weight despite adequate diets, were susceptible to illness, did not exhibit normal infant sucking habits, and appeared unhappy. Bakwin summarized failure to thrive in institutionalized infants was due to emotional deprivation.

Pringle and Bossio (1960) studied children who had been institutionalized at an early age and concluded that “our evidence suggests that the child who is rejected and remains unwanted is likely to become insecure, maladjusted, and educationally backward. On the other hand, early physical separation and prolonged

institutionalization do not necessarily lead to emotional difficulties or character defects” (p. 47).

Despite research dating back to the early 1900s, it was Bowlby’s (1966) research findings of post World War II refugees and homeless children that gained the public’s attention about the often disastrous consequences of institutionalized living. His now-famous 1951 report to the World Health Organization (WHO) is considered a classic model of the effects of maternal deprivation. According to Bowlby, the negative effects from maternal deprivation result in serious and long-standing mental and emotional health sequella. This is especially evident in the ability to form relationships with others. Bowlby stated: “. . . when deprived of maternal care, the child’s development is almost always retarded--physically, intellectually, and socially . . . that symptoms of physical and mental illness may appear . . . and that some children are gravely damaged for life” (p. 15).

Later, Harlow’s study (as cited in Greenberg, 1977) of rhesus monkeys in the 1960s found that infant monkeys who were separated from their mothers early in life had difficulties with later relationships. Using cloth-covered wire figures as mother substitutes, he also demonstrated the infant monkey’s basic infant needs for touch and warmth (Greenberg, 1977).

Results of Institutional Setting Studies: Deinstitutionalization

The foster-care system replaced institutions for many orphaned children after Bowlby’s monograph was published. Institutions for children with emotional, mental, and physical problems were scrutinized, and the environments changed (Ainsworth et al.,

1966). These studies internationally primarily impacted Korea where foster care replaced institutional care for orphaned children (S. Cox, personal communication, May 6, 1999). Despite studies on institutionalization and the changes prompted by them, however, the majority of children being adopted today come from orphanages.

Foster Care for Korean Adoptees. Provision of foster-care homes for adoptable Korean children was begun by Harry Holt and David Kim (S. Cox, personal communication, May 6, 1999) in the 1960s. They believed the care children received in Korean orphanages did not compare to that received in families. According to Cox of Holt International, "It is the foster families themselves who become the most outspoken advocates for the children and also become adoptive families as well." The foster families for Korean children receive training, education, preparation, motivation, and social reward. In addition, the communities in which these children are placed respond favorably to the arrangements.

The Health of Children Adopted From Korean Foster-Care Settings. Although Korean adoptees do present with some medical problems upon arrival into the United States, these problems are usually minor such as upper respiratory infections (Hostetter & Johnson, 1996). In the 1980s the rate of hepatitis B infection among Korean adoptees was 8%-10%, surpassed in 1990-1991 by the 20% rate among Romanian adoptees (Johnson, 1989). Since the advent of hepatitis B immunizations, however, the rate of hepatitis B infection in Korean adoptees has decreased dramatically (J. Jenista, personal communication, March 27, 2000), and Korean adoptees arrive in the United States with appropriate, documented immunization histories (Johnson & Hostetter, 1996).

Intestinal parasites are so infrequent in Korean adoptees that recommended post adoption health assessments that normally require three stool samples to test for ova parasites are reduced to one for Korean adoptees (Jenista, 1993). Adopting parents can also be assured that the birth date provided for Korean adoptees is accurate, unlike some other countries (Johnson & Hostetter, 1996). Unlike institutionalized children who lag developmentally from neglect and poor living conditions, Korean adoptees usually lag in gross motor development (e.g., sitting, crawling) because they have been carried by doting foster care mothers (Johnson & Hostetter, 1996).

Most Korean adoptees arrive in the United States with comprehensive, complete medical records that indicate they have received appropriate, quality health care in their birth country (Johnson & Hostetter, 1996). Summarizing the difference between Korean adoptees raised in foster care and adoptees from other countries where the children have been institutionalized, pediatrician Deborah Borchers (as cited in Jenista, 1999a) says: "Ten years ago, when the majority of these kids [adoptees] were coming from Korea and were in foster care, we saw a different set of children than we have now. Now children [non-Korean adoptees] are coming from such deprived conditions" (p. 1).

Institutional Living Prevails for Adoptees in Most Other Countries

Children are primarily institutionalized due to economic reasons as well as neglect or abuse that has resulted in termination of parental rights or because parents cannot care for their child's physical disabilities or medical problems (Johnson, 1997). Orphanages that place children for international adoption share some characteristics: low standards of living, inadequate health care, and high child to staff ratios (Johnson &

Dole, 1999). They are found world-wide and are of variable quality even within the same country. Although this has been known for years, it was not until 1990 when the Romanian orphanages made headlines and Americans could see for themselves how children were neglected that the impact of institutionalization was felt (Adamec, 1998).

Romanian Orphanages. Under the dictator Ceausescu's reign, Romanian orphanages of the early 1990s existed in three levels. Children were placed in orphanages based on whether they were considered normal, had mild handicaps, or severe handicaps. The quality (or lack thereof) of child care coincided with the level a child was in, with the most severely handicapped children being in the worst settings. Unfortunately, today's orphanages are not much better, and there are more orphans housed in them than ever (Groza, Ileana, & Irwin, 1999). In A Peacock or a Crow, the authors describe Romanian orphanages:

[They] were colorless, shockingly quiet and devoid of any of the usual visual or auditory stimulation that children usually receive. . . Walls were painted in dark browns, to hide the dirt. . . There were no toys. There was no exercise or exposure to the outside. Most of the time, the children did not have enough to eat or drink. . . most children were below the twentieth percentile for height and weight. . . some staff said that mortality rates in the winter could reach 40%. Recent information suggests that 50% died within the first 24 months. . . [there were] inadequate child-to-staff ratios ranging from 8:1 to 35:1. . . Crying was ignored, both as policy and as a natural reaction to so few staff caring for so many children. The staff provided minimum touching and handling of the children. . . many would become autistic-like--having a blank stare, rocking back and forth, and looking constantly at their hands (p.33-35).

Russian Orphanages. Orphanages in Russia and the other the former Soviet Republics are very regimented with children being segregated by age. Strict schedules are kept for everything, including toileting times. In her personal diary recorded during

the summer of 1999, Lydia Stickney (1999) wrote about her experiences visiting and working in Russian orphanages. At the orphanage at Votkinsk, children were treated lovingly, and the Glaznov facility was "... meticulously clean, [with] hot meals ... and ... a plentiful supply of towels, underpants, and diapers (cloth) ..." (p.25). However, despite these positive impressions, three things were apparent to Stickney: the children no longer reacted to physical pain, their needs for parental love were unmet, and they seemed depressed (p. 25). She described the orphanage at Izhevsk as "... large, impersonal, and cold. It fails to adequately address the needs of the orphans. It deserves the label 'institution'." (p. 26). Developmentally, the children in this orphanage lagged behind children in the orphanages at Votkinsk and Glaznov (1999).

Chinese Orphanages. Orphanages in China can range from chaotic with adults only infrequently present, to being efficiently run with a high caretaker to child ratio. Handicapped children remain together from the age of three years old (J. Jenista, personal communication, February 19, 1999).

In A Passage to the Heart: Writings From Families With Children From China.

Katharine Hayner (1999) describes the Chinese orphanage from which her daughter was adopted:

The orphanage consisted of three small rooms containing a total of 28 children ... the concrete floor was not carpeted and walls were unpainted. The area that would have been the bathroom was without fixtures ...

Our daughter's room contained five green-painted cribs, a cot, and a wooden bench of potty chairs ... There was a clothesline along the wall that have various colorful rags hanging on it ... A few would-be toddlers were in walkers that were tethered to the cribs with a one- to two-foot-long cord ... A back door led to an enclosed porch where the older children played in their walkers on sunny days ... Two babies shared each bed, feet to feet. All were lying their

backs with arms sticking straight up, hands covered by long sleeves, and heavily clad in knit clothing . . .

Clean clothes were put on every few days . . .

Care givers . . . seemed to give all the babies attention . . . Babies were fed . . . on a schedule . . . a cow's milk- based formula . . . mixed with a rice cereal . . . This very hot formula was fed to them through a standard nipple with a rather large hole in it. Bottle-propping was standard practice. It took most babies less than five minutes to gulp their fill of 8 ounces. After feeding, they were put in a free spot on 'potty row' . . . once a baby 'produced,' she . . . was put back in bed—lying on her back" (p. 49).

The Health of Children Adopted From Orphanages

The following studies were of children adopted from outside the United States.

Adopted children may represent those with the best potential for survival and the fewest health problems among orphaned children. As such, they may not be representative of all children who are available for adoption. Some of the children included in the following studies were from foster care settings (e.g., Korea, Colombia) and so may have better outcomes than orphanage children. Unless specified otherwise, growth parameters used in the following studies were assessed using World Health Organization growth charts.

A study of the health of 293 internationally-adopted children representing 15 countries identified 57% with medical problems. Most diagnoses were made by screening tests for them, rather than from history or physical exam. Seventy-three percent of the diagnoses were infectious diseases, including intestinal parasites, hepatitis B, and tuberculosis (TB). What is most disturbing about these statistics is that more than half of the children identified as having a medical problem in this study had been previously examined by a physician in the United States (Hostetter et al, 1991).

Jenista (1998) summarized the types of short-term infectious diseases an internationally-adopted child may initially have when adopted; these include diarrheal diseases, hepatitis A, helicobacter pylori, intestinal parasites, lice, and scabies. Although rare in adopted children, malaria and measles are occasionally detected. Chronic infectious diseases that may be present include cytomegalovirus (CMV), hepatitis B, hepatitis C, hepatitis D, human acquired immune virus (HIV), TB, and, rarely, parasites that may not be evident until later in life. These include paragonimiasis, schistosomiasis, and neurocysticercosis. Finally, there may be learning disabilities and conditions resulting from drugs, including alcohol and other prenatal exposures (Jenista, 1998).

A study of international adoptees representing 22 birth countries were examined at the International Adoption Clinic at the Floating Hospital for Children in Boston, Massachusetts. Only half of the children studied were developmentally normal. Those with medical problems had more growth and developmental delays than the healthy children and the severity of developmental delays increased as growth parameters decreased (Miller, Kiernan, Mathers, & Klein-Gitelman, 1995).

Most recently, researchers (Ames, 1997) concluded that the results of their study of Romanian orphanage children were consistent with earlier studies of orphaned children. Ames said:

... while most people dealing in international adoption acknowledge that a better job of rearing children in institutions is being done in some countries ... there is a disturbing sameness to all the studies of institutional-reared children from the 1940s to the present. Few of our results are completely new" (p. 109).

Ames cites studies describing medical problems among international adoptees including malnutrition and small size, developmental delay, and specific behaviors as being consistent findings in her study of Romanian orphans adopted by Canadian citizens.

The Health of Romanian Adoptees. In a study of the behavior and development of Romanian adoptees adopted to Canada between January 1990 and April 1991, 78% were identified as lagging in all areas of development when adopted (Morison & Ellwood, 1997). Fifty-nine percent of the children were below the 5th percentile for weight at the time of adoption based on both North American and Romanian norms (McMullan & Fisher, 1997 as cited in Fisher, Thompson, Ferrari, Savoie, & Lukie). In another study of Romanian adoptees, initial growth assessments indicated similar delays (Benoit, Jocelyn, Moddemann, & Embree, 1996).

Medical problems (85%), such as intestinal parasites, hepatitis B, and anemia, were reported to be present among adoptees in the Canadian study (Fisher, Thompson, Ferrari, Savoie, & Lukie, 1997). During the 11 months post adoption, eating problems were identified in 30% of the children. Additionally, the children were noted to lie in bed when awake instead of giving some sign that they had awakened. Repeated behaviors, such as rocking and studying fingers and hands were also noted (Fisher, Thompson, Ferrari, Savoie, & Lukie, 1997). Finally, many of the adoptees in the study exhibited "indiscriminately friendly behavior" (friendly with strangers without the usual caution) (Chisholm & Carter, 1997).

A United States study (Johnson et al., 1992) of Romanian adoptees found abnormalities in 85% of the children. Thirty-four percent of the children had growth

failure. Hepatitis B infection was discovered at an incidence of 50 times greater than that of the children born in the United States (and four times higher than non-Romanian international adoptees). Intestinal parasites were identified in 33% of the children (compared with 22% in non-Korean adoptees). Many of these findings were attributable to orphanage life (Johnson et al., 1992).

The Health of Russian Adoptees. Medical records at the University of Michigan International Adoption Clinic suggest that the rates of infections from syphilis, fetal alcohol syndrome (FAS), and poor health in general are high among Russian adoptees. The rate of syphilis is close to 14%. Alcohol use by birth mothers is mentioned in medical records 12% of the time. A range of 3 to 5% of internationally-adopted children seen in United States international adoption clinics are diagnosed with or suspected of having FAS, which is 10 times the rate in the general Russian population (Jenista, 1999c).

A study (Albers, Johnson, Hostetter, Iverson, & Miller, 1997) of children adopted from the former Soviet Union and Eastern Europe (Poland and Bulgaria) found frequent developmental delays. Fine motor skill delays were seen most frequently (82%), followed by gross motor skill delays (70%), language skills (59%), and social skills (53%). Significant growth failure was also noted with one month of linear growth delay for every five months a child was institutionalized (Albers et al., 1997).

The Health of Chinese Adoptees. In a study of 192 Chinese adoptees, growth and developmental delays were found. Weight delays tended to increase after the age of six months, and height and head measurements revealed progressive delays throughout

infancy. Global developmental delays were discovered in 44% of the children studied (Miller, 1999).

Johnson and Traister (1999) collected data between January 1991 and October 1998 on 357 children adopted to the United States from China. They discovered that 74% of the 136 children were delayed in at least one area of development upon arrival into the United States. A month of growth was lost for every 2.5 months of orphanage life. The researchers determined that micronutrient deficiencies, growth failure, lags in developmental growth and exposure to lead were more prevalent than infectious diseases such as TB and hepatitis B (Johnson & Traister, 1999). Evidence of lead exposure was found in 13% of Chinese adoptees in another study (Aronson et al., 2000).

Implications for Adoptive Families

Johnson (1997) gives the most candid appraisal of what to expect of a child adopted internationally from a health standpoint:

Let me be blunt. The chance of an institutionalized child being completely normal on arrival in your home is essentially zero! . . . Kids aren't in orphanages because they come from loving, intact families with a good standard of living and ready access to good health care and nutrition. Abandonment by a destitute, single parent with poor prenatal care and inadequate diet is the most common reason why a child is available for adoption. The second most common reason is termination of parental rights because of neglect and/or physical/sexual abuse (often alcohol related). Over 50% of institutionalized children in Eastern Europe are low birth weight infants, many were born prematurely, and some have been exposed to alcohol *in utero* [sic]. Finally, children with major medical problems or physical handicaps may be placed in orphanages by their parents due to limited access to corrective treatment and rehabilitation services. These kids are a high-risk group [sic] by any standard (p. 27).

Johnson concludes that all institutionalized children lag in gross and fine motor skill development, language, and social skills. Some children have difficulties with

attachment. All physical growth is retarded. In most cases prenatal information is not available or is insufficient (Johnson, 1997).

The Adoption Experience: Studies of Families' Perceptions

Although the preadoption process is meant to provide a picture of the prospective adoptive parents, adopters do not always feel that they have a clear picture of the child they will be adopting. In The International Adoption Handbook, Alperson (1997) cites parental feelings of anxiety and loss of control due to the unpredictability of the adoption process (Alperson, 1997). Information on bonding (Smith & Sherwen, 1983) indicates that specific preparations for the addition of a child to a family can enhance the relationship between mother and baby.

However, unlike the biologic mother-to-be who may be assisted by a health care provider in accessing health information, education for adoptive parents is "an essential part of the [agency] placement worker's role . . ." (Zeigler, 1996, p. 3). Kay Donley Zeigler, M.S.W., refers to this information as "disclosure". Providing information is dependent upon many factors, including agency policy, information availability and accessibility, and the ability to assist families in realizing the implications of the information they receive. The information needs to be meaningful, which involves interpreting information in addition to providing it (Zeigler, 1996).

Reflecting on their adoption experiences, some parents cited areas about which they would have liked more information. These areas included: a) information and support, b) parenting skills, c) breast feeding an adopted child, d) learning how to assist

the adopted child to make secure attachments, e) medical issues, f) the importance of finding professionals/specialists and g) sharing adoption plans. Information and support revolved around attachment, institutionalization, fetal alcohol syndrome, and racism issues. One mother recommended attending as many support group events as possible (Fancott, 1999).

Knowledge about medical issues, such as recommended screening tests and seeking out professionals who are knowledgeable about adoption, were also seen as important. Finally, sharing what adoptive parents are learning and have learned about adoption (e.g., use of appropriate adoption terminology) with others helps to adjust to the many facets of adoption as well (Fancott, 1999).

In a study by Smith and Sherwen (1983), adoptive mothers stated they did not feel they had enough time to prepare for their child's arrival and, thus, felt unprepared when it was time to actually adopt. Some mothers in this study stated they felt "deceived" (p. 137) by their adoption agency because the child they adopted was not the child described. Smith and Sherwen point out that the correct information was often given, but parental perceptions and expectation prior to adopting had not been realistic.

The results of a 1985 questionnaire (Jenista, 1986) of adoptive parents' perspectives on medical issues related to intercountry adoption indicated that parents' perceptions of health issues differed from physicians' perceptions. Although parents expressed general satisfaction with the health care their child received, many diagnoses were delayed, some as long as two years. The majority of medical conditions were not related to the child's country of origin. Parents reported needing more information about growth and development, specific medical conditions, orphanage life, and tests and

evaluations a prospective adoptee would need once in the United States. They also requested reading lists, parent class resources, referrals to physicians, and information about government programs to provide medical assistance (Jenista, 1986).

In that same study parents rated sources for medical information. The resources categorized as “best” or “very helpful” were varied and included private doctor or dentist followed by social worker, parents’ own experiences, medical records arriving before or with a child, other adoptive parents, relatives, or friends, and United States agencies. Less often, information was obtained from OURS Magazine (an acronym for “ours for a united response,” now known as Adoptive Families Magazine), parent support groups, specialist physicians, foreign agencies, adoption or expectant parent classes, Today’s Child (an agency manual for children adopted from India) and HELPLINE (a parent support line run by Adoptive Families of America). Resources were cited as being only partially helpful, however, and parents expressed a need for better medical preparation about the breadth of conditions and issues that an internationally-adopted child presents (Jenista, 1986).

A study by Edwards (1987) about biologic and adoptive parent needs revealed that adopting parents perceived themselves as having fewer needs than biologic parents. This is in contrast to the popular belief that adoptive parents are “needy and insecure” (p. 233) and stresses the need to individually assess families for their specific educational needs (Edwards, 1987).

A cross-sectional survey (Groza & Ileana, as cited in Goldstone, 1999) of approximately 24% of families that adopted from Romania between 1990 and 1993 found approximately half of the children in the study lived in an orphanage prior to

adoption. The study revealed that 91% of respondents rated the effects of the adoption on their family as positive. Thirty percent reported the process was not as smooth as anticipated. Between 45% and 60% of respondents also indicated not having received adequate social and health information about the child they adopted. Although the majority of respondents did not report apparent problems, 12% reported health problems were more serious than they were led to believe.

Groza and Ileana (as cited in Goldstone, 1999) also reported that more than half of the parents did not feel they had been given adequate information about the specific child they were going to adopt. Sometimes the information was completely false and that the child they adopted differed from the preadoption vignette they had received (Groza & Ileana, as cited in Goldstone, 1999). This can be emotionally upsetting, considering that many parents anecdotally report bonding with the referral photograph of their child prior to adopting (Johnson & Hostetter, 1996). Today in China it is not unheard of for a referral child to be replaced with a different child when presented to the prospective parents for adoption. Although this has probably never been published, there have been anecdotal reports to International Adoption Clinics by adopting parents of such practices occurring (J. Jenista, personal communication, April 23, 1999).

The Adoption Experience: Anecdotal Reports

As more and more children are being adopted internationally from institutions, feelings of anger and being deceived have been voiced. Some adoptive parents are claiming they were unaware and unprepared for the child they adopted. An article titled "Families in Crisis: When Foreign Adoption Goes Wrong" (Ohlson, 1998) details the

practices of an Ohio-based adoption agency which did not inform prospective parents of potential problems children adopted internationally could experience. In fact, the authors state that the article was originally being researched as a story expecting a happy ending, but the report identified many families who did not see themselves as living “happily ever after” (p. 78) post adoption. Without knowledge about the effects of institutionalization, many parents felt unprepared for the problems they later discovered with their children (Ohlson, 1998).

An article in The Boston Sunday Globe (Sennott, 1996) told of a family who adopted from a former Soviet Republic, only to find that the baby was brain damaged. Another article, “International Adoptions: Can Love Beat the Odds?” (Deane, 1997) discussed the potential for developmental, mental, and emotional problems when adopting an institutionalized child whose birth family history is usually not available. However, even when provided with appropriate information, agencies reported that prospective adoptive parents still choose to adopt (Deane, 1997).

Unpreparedness certainly was evident in a flurry of e-mail messages in an adoptive parents’ forum on American Online (April 29, 1996). Parental dissatisfaction centered on parents’ inability to obtain relevant health information, feelings of unpreparedness for the health problems of their children, and feelings of mistrust directed at adoption agencies. In commenting on the outcomes of 13 families working with a Christian adoption program, the e-mail author commented on the futility of trying to get reliable health information about a prospective adoptee:

... all of the 13 families have been through HELL! [sic] ... 1 family is considering a DISPLACEMENT [sic] of the adoption, 1 family is in DIVORCE, [sic] 5 families have gone through BANKRUPTCY, [sic] 10 families are in

CRISIS COUNSELING, [sic] and at least 5 of the couples say they HATE [sic] their child and would have never of [sic] adoptive [sic] them if they knew what was a happen [sic] . . . DO NOT FOOL YOUR SELF! YOU CAN ASK ALL THE MEDICAL AND FAMILY QUESTIONS YOU WANT, BUT THE TRUTH IS THAT THE DIRECTOR DOES HER JOB FOR MONEY AND SHE WILL TELL YOU ANYTHING. THEY DO NOT DO GOOD RECORD KEEPING. MOST OF THE INFORMATION [sic] YOU ARE GIVEN WILL BE VERBAL AND MAY OR AMY [sic] NOT BE THE TRUTH. SO IT'S LIKE THIS WHEN YOU GET TO THE STATES YOU ARE STARTING FROM SCRATCH . . . [sic] (American Online, April 29, 1996)

Another detailed health problems parents felt unprepared for as well as mistrust of adoption agencies:

. . . my child . . . has a positive TB exposure [sic] . . . eye problems (which need surgival [sic] correction, but can't because of her heart), she has cardiomyopathy (the only corrective surgry [sic] is a transplant), speech and language disorders, developmental delays, senory [sic] intergration [sic] disorders, microcephaly, Fetal Alcohol Sysdrom [sic] , she suffers from short status (she is smaller than a 3 year old and her legal birthage is 6) . . . we have been to hell and back with attachment disorders [sic] problems . . . PLEASE, PLEASE [sic] heed my worrying. And if you won't believe me ask someone else (but NOT [sic] your agency; they are in this for the money not the truth). [sic] (American Online, April 29, 1996)

The problems parents reported occurred in many countries. One parent wrote, asking for understanding and compassion from those who had not had these experiences.

The author also expressed fear of reprisal for voicing unhappiness and concerns and used this as rationale why many parents did not tell others how they really felt:

My son is coming out of the dark after several extremely difficult years and this was as a result of orphanage life in Guatemala. It's not just Russia or Romania. Until you have walked a mile in the shoes of someone who has lived this, you cannot begin to understand. This is essentially why people don't talk about it, . . . they know they will be judged, and judged harshly by those who couldn't begin to grasp the enormity of having the courage to face another day when you have the intensity of the problems that can be manifested from neglect upon your child.

I beseech to those who think this is about, [sic] lack of love, lack of parental involmnet [sic] or any other human quality, . . . it's not . . . I tell you from the depths of my soul this woman needs support . . . (American Online, April 29, 1996)

And yet others wrote different, positive accounts of their experiences: “. . . rest assured that some of us (probably many) have had very positive outcomes” (American Online, April 29, 1996). Another wrote: “I adopted a daughter from Moscow, my agency was VERY [sic] upfront [sic] about ALL [sic] the possibilities that existed. She is now four years old and perfect in every way (healthwise) [sic]” (American Online, April 29, 1996). Not deterred, prospective parents have continued to adopt internationally, as increasing international adoption numbers indicate (U.S. Immigration and Naturalization Services, 1999).

Once the adoption is complete, adopting parents also have different perceptions of the health assessment they receive for their new child. Jenista (1999a) describes some parents viewing the initial assessment as an “obstacle” before “living happily ever after” (p.1). Others approach the visit as a way to receive approval for adopting the “right child” (p.1). Parents may dismiss physician concerns, citing the physician’s inexperience with international adoptees. Any issues raised at that visit may also evoke parental feelings of guilt for not identifying a problem themselves. In contrast, if the health care provider does not voice any concerns, parents sometimes think that their worries have been ignored (Jenista, 1999a).

The Need to Prepare Families

Adopting does not solely involve learning to physically care for and raise a child. It also has other implications. Lancaster (1994) states that adoption means: “. . . accepting that your child entered your life in a way that differs from most family-building situations . . . with a heritage of his own that includes another set of

parents . . . a cultural, social, and medical heritage different from your own” (p. 134).

How well families adjust to an adopted child joining them has a lot to do with the family’s preparation for the adoption (Lancaster, 1994).

Smith and Sherwen (1983) hypothesize that there are similarities between how biologic parents and adopting parents adjust to a new child. They likened the phases of becoming an adoptive parent to the phases of becoming a biologic parent as identified by Klaus and Kennell (as cited in Smith & Sherwen, 1983). These phases are depicted in Table 1.

Table 1: Pregnancy and Adoption Phases

Biologic Phase		Adoptive Phase	
Time 1	Prior to pregnancy	Time 1	Prior to entry (preadoption)
Time 2	Pregnancy	Time 2	At entry (adoption)
Time 3	Birth	Time 3	After entry (after adoption)
Time 4	After Birth		

Results of their study showed that during Time 1 biologic mothers-to-be often fantasized about their expected child and potential circumstances they might encounter. Fantasizing is a way to reduce anxiety through problem solving ahead of time. This sort of thinking, when it is positive, is believed to be important in preparing the mother-to-be for nurturing behaviors later (Smith & Sherwen, 1983).

On the other hand, lack of fantasizing is thought to make bonding with the child more difficult. Almost half of the adoptive mothers in Smith and Sherwen’s study stated they did not fantasize about their expected child. Some admitted to actively suppressing fantasies, fearing the adoption would not take place or because they received short notice

about the impending adoption and did not have time to think about the child specifically (Smith & Sherwen, 1983).

The bonding process in Time 2 for biologic mothers is affected by the mother's ability to care for the baby once it is born and the support she receives. For adoptive parents there is an association between the adoptive mother's response to seeing the child the first time. When it is positive, attachment is easier. The majority of respondents in the study reported positive responses to initial meetings with their children (Smith & Sherwen, 1983).

Other reactions at the first meeting included ambivalence, disappointment, and negative feelings (e.g., frightened, uneasy, awkward, inadequate). These reactions correlate with those of biologic mothers who are surprised by a baby who is not what was expected (e.g., different gender). When there are discrepancies between a mother's expectations and reality, both biologic and adoptive mothers may have more difficulties in bonding with their babies (Smith & Sherwen, 1983).

Once a child is in the adoptive home (Time 3), the interactions between the mother and child are important to bonding. Verbal and non-verbal communication, nurturing and claiming behaviors, physical closeness, and doing things together seemed to promote the bonding process (Smith & Sherwen, 1983). Melina (1998) refers to claiming behaviors as ways that parents see the child as being like them. Often, for adoptive families this may mean finding physical similarities or mannerisms that are like other family members (Melina, 1998).

Smith and Sherwen's (1983) study revealed what mothers perceived to be distancing factors which decreased attachment between mother and child. These

included behaviors by the child that the mother perceived as negative (e.g., lying, stealing, setting fires), detached, or rejecting. Mothers also cited feeling anxious, fatigued, and having role conflicts as other reasons for feeling distanced from their child (Smith & Sherwen, 1983).

Summary

According to adoption experts, the majority of parents are happy with their child(ren) and their adoption (Johnson & Hostetter, 1996). However, as Johnson (1997b) warns, all internationally-adopted children raised in orphanages are at risk for the negative effects of institutionalization. Studies on the health of internationally-adopted children, the majority of who come from orphanages in countries where there is a low standard of living and virtually nonexistent health care, indicate that many of these children have a myriad of health problems (Johnson, 1997). Reports from international adoption clinics, where these children are assessed, report that these conditions are often undetected by health care providers who initially assess these children (Ames, 1997; Hostetter et al., 1991).

Although many of the children have made great strides in “catch up” development once in the United States, what is unknown are the long-term effects of early life deprivations especially in the areas of attachment, intellect, language, sensory hypersensitivity, and social development. Although many of today’s families adopting internationally recount their experience as positive, the children who are adopted still have needs that differ from U.S. born children (Johnson & Hostetter, 1996).

Anecdotal reports from parents and the few studies that have been done to assess the preparedness of adopting parents for the health concerns and negative effects of institutionalization strongly suggest that this is an area that needs to be improved. The perceptions, attitudes, and feelings adopting parents have about their preparedness to adopt based on the type and usefulness of health care information they received during the adoption process can be used to direct efforts to better prepare families.

Some parents will knowingly choose to adopt a child with health problems. For others, adopting a child with problems parents did not anticipate or for which they were unprepared, may not be in the best interests of the child or the adopting family.

Adequate information and preparation, however, can make a difference for families in how they approach and perceive the ramifications of adopting a child with an unknown past. Finally, with appropriate and useful information, parents can be supported to advocate for the specific needs of their child and the adoptive family and, ultimately, improve the health of children adopted internationally.

Conceptual Framework: Advocacy

The conceptual framework for this study was the concept of advocacy. The dictionary defines "advocate" as "to write or speak in favor of or support" (Webster's Dictionary, 1997, p.7). Kohnke (1982) stated, "The role of the advocate is to *inform* [sic] the client and then to *support* [sic] him in whatever decision he makes. . . Support means that when the client makes a decision, the nurse abides by it and defends his right to make it" (p. 2). It is Kohnke's model of advocacy that was the foundation for the conceptual framework.

Kohnke's advocacy model (Figure 2, Appendix B) contains 10 categories. These include "(1) informing and supporting, (2) systems analysis, (3) social ethics, (4) ethics, (5) issues, (6) medical-industrial complex, (7) social laws, (8) politics, (9) professional education, and (10) professional practice" (Kohnke, 1982, p. 3). Although all ten components of the advocacy model can be applied to different aspects of adopting internationally, the focus for this study was on the "informing and supporting" category which Kohnke considered to be the two functions of the advocate (Kohnke, 1982).

Informing and supporting involve a desire to provide information to a client, having a client who desires to have the information, and being aware if others do not want information shared with a client. It is important that information provided is accurate and presented in a way which is significant to the client. Providing informed consent is not a reflection of the nurse's opinions or beliefs or the opinions of others (whose goals may be different than the client's) and as such, helps the client to make health decisions which are in his best interests and meet his personal needs (Kohnke, 1982).

Parents adopting internationally need information about the specific child they are considering for adoption as well as the health issues and concerns regarding the effects of institutionalization. This is important because, ultimately, it is the parents who make the decision whether or not to adopt a specific child. "No one's best interests will be served if a family accepts the referral of a child whose needs are greater than the family's ability to parent" (Johnson & Dole, 1999, p. 36).

"Support" means accepting the decision the client makes even if it is not one the nurse would choose. In this way the nurse, serving as an advocate, refrains from

“rescuing” the client by making the decision and accepting responsibility (Kohnke, 1982). Melina (1998) underscores this responsibility. She states that: “When seeking help from professionals, the parents should remember that . . . only they are responsible for the child and should make the final decisions” (p. 281).

The nurse can be a valuable resource to parents by having an awareness of potential problems and knowledge about relevant resources and referrals. This information can assist and support parents in meeting the health care needs of the child they adopt (Mitchell & Jenista, 1997). Support can also be provided by encouraging families to develop a knowledge about international adoption and identify a reputable adoption agency that provides preadoption and post adoption services and by seeking interventions early when a problem is identified (Johnson & Dole, 1999).

Kohnke’s (1982) other categories, 2 through 10, are summarized here to provide a full picture of her model. The category of “system analysis” involves analyzing the client’s goals, those of others involved with him, and the system in which he operates. It is a way to assist the client to make changes when necessary to reach goals without totally disrupting the system. This type of analysis requires a knowledge and understanding of the client and his role in the system, how the system works, and what the client and the system’s implicit and stated goals are (Kohnke, 1982).

System analysis means knowing the client and the system well enough so that there is little risk in incorrectly deciphering the client’s needs. It also means the nurse is responsible to communicate with others in the system in order to reduce the risk of confrontations and confusion as to the nurse’s specific role and goals. This is especially important in avoiding “turf” wars with other health professionals (Kohnke, 1982).

In the third category, "social ethic," decisions are made based on how the client views what his rights are and the principles that underlie them. Knowledge of the social ethic of the client helps in understanding the reasons why clients make certain decisions and may help nurse advocates accept client decisions even when not in agreement with those decisions. The fourth category, "ethics," is related but broader than the social ethics category and involves the nurse's professional standards guided by the code of ethics for the nursing profession. The Patient's Bill of Rights provides an ethical basis for client expectations from the medical system (Kohnke, 1982).

The "issues" category in Kohnke's concept of advocacy involves how factors such as race, sex, and age, affect access to education and the health care system. This can influence decisions made by individuals and groups. The issues category essentially deals with how prejudices affect whether or not an individual is fully informed or is allowed the opportunity to make a decision. When advocating for a client, then, awareness of unspoken viewpoints by others about that person can be crucial (Kohnke, 1982).

Kohnke's sixth category, the "medical-industrial complex," is an example of how advocating for a client can impact on the part of the medical system with which he is or has been involved. Sometimes, as a result of advocating for the client, the need for the medical system or some part of it may no longer be necessary. On an individual basis the ramifications may not be great. However, on a large scale these types of decisions could affect the viability of various programs and institutions, ultimately affecting health care for the population at large (Kohnke, 1982).

When advocating for a client, “social laws” can influence individual and group decision making. Likewise, politics can affect the advocate’s ability to assist clients by either passing legislation that creates advocacy barriers or removes them. Informed consent laws and legislation which guard the advocacy process, help to underscore the importance of providing information and support for clients so that they can make informed decisions about their health care. The ninth and tenth components of Kohnke’s model, “professional education” and “practice,” refer to the importance of society having knowledge about what a nurse’s education prepares her to do as well as how the practice area (e.g., the clinical setting) can affect a nurse’s role (Kohnke, 1982).

Finally, Kohnke’s model proposes three levels of advocacy. These include advocacy for oneself, advocacy for the clients, and advocacy for the community. In order to advocate for others, one must be knowledgeable about oneself and what is being advocated for, be able to make an informed decision, and accept the consequences of choices that are made. These responsibilities can be transferred to clients. When advocating for the community, the nurse has a responsibility to advocate for self as well as others and share the responsibility for information provided and decisions made (Kohnke, 1982).

The type and amount of information available to prospective adopting families varies from country to country and even from institution to institution within the same country. Many families who adopt internationally must accept a child with unknown family, social, and past medical histories due to exposures in the birth country or being raised in orphanages. Supporting families in their decision to adopt a specific child not only involves acceptance of their right to make the decision, but also includes working

with them to obtain additional information, resources, and referrals. It is, therefore, important to know what information is helpful for adopting parents at different times in the adoption process and how this information can be accessed.

CHAPTER 3

METHODOLOGY

Project Design

Focus group methodology was used in this qualitative study to explore (a) parental perceptions, attitudes, and feelings regarding the preparation and type of health care information families received during the adoption process and post adoption and (b) parent assessments of the usefulness of this information in preparing them to identify health care needs and access appropriate resources when adopting internationally.

Target Group

The target group was parents who had adopted internationally in the past 10 years. The 10 year limit in which the adoptions took place encouraged participation of families who had adopted from several different countries, including Korea which was the main source of adoptable children prior to 1995. Today, participating countries are more equally represented in international adoption. In addition, 10 years was used because some health concerns (FAS, neurological problems or learning difficulties) may not be apparent until the child is older and possibly in school, and this time frame would encourage parents with school-aged children to participate.

There is no single source which identifies families who have adopted in Montana, so no attempt was made to obtain a random sample of adoptive parents. The subjects

were recruited using the snowballing technique (network sampling) which uses social networks to obtain study participants (Talbot, 1995). Three separate focus groups were formed, and each group met on a different day. When both parents desired to be in a focus group, they were placed in different groups. Group size was initially limited to no more than eight participants which Morgan (1988) describes as a moderate-size group. Six parents were present at the first two group meetings, and five parents attended the third group.

Procedure

Participants signed a pre-inclusion letter (Appendix C), completed a non-identifying demographic questionnaire (Appendix D), and met on predetermined dates and times. Participants were given a choice of 3 different dates and times from which to choose for a meeting. The study took place in a Montana State University–Bozeman, College of Nursing campus meeting room reserved for this purpose. Each group of participants met for approximately 2 hours as recommended by Morgan (1988). The sessions began with introductions, followed by a review of the pre-inclusion letter. Audio taped discussions were stimulated through the use of open-ended questions (Appendix E).

At 30 minute intervals the tape recorders were turned off and participants were asked to fill out a 3x5 card with any questions, comments, or concerns they had but which they did not feel comfortable voicing. So that individuals who wanted to participate in this way were not identifiable, all participants were asked to write

something even if only a line or two from a nursery rhyme. Card comments were then incorporated into the discussions so that their source was not known to participants.

The audio tapes of the focus groups' interactions were later transcribed for analysis purposes. The tapes, demographic questionnaires, and 3x5 cards were then stored in a locked file cabinet in the College of Nursing, Office of Research, where they will reside for two years before being destroyed. Copies of the master's degree written project copies will be made available for reading by focus group participants and others.

Data Analysis

Inductive, thematic analysis was used to interpret focus group responses. Analysis was done in two phases. In Phase I, focus group responses were grouped into themes and categorized, based on applicability to different time periods in the adoption process: I-Prereferral, II-Referral to Placement, or III Postplacement. Category IV referred to general advice. The responses were then analyzed for meaning, consistency with findings in the literature, and new or unexpected information. In this phase of interpreting the data, each question asked of focus group participants was also examined for appropriateness in meeting the objectives of this project.

Focus group responses were analyzed to determine the applicability of using Kohnke's advocacy model for this specific population. Finally, descriptive statistical analysis using percentage frequencies was used to analyze the information provided by the demographic questionnaires (See Table 15 Appendix F and Table 16 Appendix G).

Rights of Human Subjects and the Consent/Review Process

Prior to initiating this study, approval for this research was obtained from the Montana State University College of Nursing Human Subjects Review Committee. Parents who expressed an interest in participating in the study were sent a pre-inclusion letter (Appendix C) which informed them of voluntary participation and notified them that they were free to withdraw from the study at any time. Group participants also signed a letter agreeing not to divulge specific, individual concerns or statements expressed by group members in any way that could make their identity known.

Participation Benefits

Participating in the focus groups provided many benefits. Participants had an opportunity to have a positive effect on dissemination of health care information, based on their personal experiences. Taking part in the focus groups provided participants with the opportunity to get to know other parents of internationally-adopted children with a possible common history. Finally, participation encouraged discussion of perceptions, attitudes, and feelings about health care information that was provided (or not) during the adoption process from a variety of sources. For those who had a negative experience with this part of adopting, the focus group format may have served as a form of emotional catharsis.

Participation Risks

There was risk of breaching confidentiality by identifying an individual as a source of potentially sensitive information. Likewise, it was possible that group

interactions would evoke emotions that caused an individual discomfort. With this in mind, the pre-inclusion letter included the option of withdrawing from the study at any time without giving reason (Appendix C), filling out 3x5 cards for anonymity purposes, and participants were provided with adoption support resources.

CHAPTER 4

PROJECT OUTCOMES

Phase I: Data Themes

In this phase of data and interpretation, thematic, inductive analysis was used to interpret focus group responses. Each of the themes was categorized by question and grouped into adoption process time periods: I-Prereferral, II-Referral to Placement, or III-Postplacement. The last question, which asked for advice for prospective adoptive parents, was categorized by theme only and not differentiated into time periods.

Subjects

Study participants were divided into three groups based on their availability to meet on one of three days/dates/times that were provided and based on reserved room and researcher availability. When both parents in a family wanted to participate, they were placed in separate focus groups. The three focus groups were comprised of 17 adoptive parents—six were in the first two groups and five were in the third group. The parents represented adoptions totaling 29 children, 58.6% of whom were adopted from Korea, and 41.2% of whom were adopted from seven other countries outside the United States (see Table 15 Appendix F and Table 16 Appendix G).

Focus Group Questions

Group discussions were conducted with open-ended questions:

1. What kinds of health information did you receive (before, during, and after adoption)?
2. In what ways were you supported by your health care provider in your efforts to obtain more information, access resources, or obtain referrals and other ways to advocate for your child's health needs (before, during, and after adoption)?
3. What other sources did you find helpful in supporting the above efforts (before, during, and after adoption)?
4. Which resources/information utilized in response to question 3 were most helpful and why (before, during, and after adoption)?
5. If you were going to adopt again or give advice to prospective adopting parents, what information would you insist they access? What other advice would you offer?

Parents were asked the first four questions in time frames, based on the adoption process. "Before adopting" referred to any time prior to receiving an adoption referral and was coded "I. Prereferral". "During adoption" referred to the time period from receipt of an adoption referral for a specific child to placement with the parents and coded "II. Referral to Placement". Placement was used as a time frame instead of when adopted because the process of legally adopting once in the United States is sometimes delayed for many months after leaving the country of origin. Finally, the period "after adoption" referred to the time after the child was in the adoptive home and was coded

“III. Postplacement.” The fourth category, which asked for parents’ advice, was coded as “IV. Advice.”

The following tables indicate the questions asked and the time frames they addressed. Responses were categorized into themes, and specific focus groups that provided the responses were identified.

Additional comments and questions which were received on five 3x5 cards included:

1. A request for the names and numbers of “international doctors.”
2. A comment about difficulties with extended family reactions to adopting a child with a medical issue.
3. A question, “what about circumcision?”
4. A comment that a parent felt informed as much as could be expected for an adoption and that their agency “prepared us well.”
5. A parent indicated that the United States Consulate asked whether she was aware that her child’s birth mother had an “incurable disease”. This was something she had not been told by the agency, but something which she believed the agency had to have had knowledge about. These comments and questions were interwoven into interactions and became a part of the data in this project.

Analysis of Focus Group Data

Thematic, inductive analysis was used to analyze the data. Audiotape transcripts were reviewed, coded, and then categorized into themes for each question in each time

frame of the adoption process. Major themes that emerged are listed in Tables 2 through 14.

Findings

Table 2. I. Prereferral

Question 1: What kinds of health information did you receive before adopting?

Response Themes	Group 1	Group 2	Group 3
1. Knowledge about the health of prospective adoptees in general.	X	X	X
2. Expectations about the types and amount of health information that would accompany the referral of a specific child.	X	X	X
3. An understanding that the amount of social information about a specific child referral would be limited or unavailable.	X		X

The first category of responses, "Knowledge about the health of prospective adoptees in general," included impressions about how adoptable children were cared for in their country of origin, the general health condition of the children, and potential health concerns/issues. These perceptions were obtained from information provided by adoption agencies, articles in adoption magazines, books, from other adoptive parents, and from the Internet.

In commenting on how the children were cared for, one parent perceived that children were well-cared for in a particular setting because it was "Christian-based." Another child was known to be in foster care, which the mother equated with better than

being in an orphanage because the child would be able to bond easier with the adoptive parents. Regarding general health and physical condition of children prior to being adopted, one parent stated that she expected her child to have “special needs” simply because she had agreed to accept a “special needs” child in order to qualify to adopt because this was not her first time adopting.

Parents adopting specifically from Korea commented that: “Adopting from Korea . . . is a lot different than adopting from some other countries . . . most of the children are well babies . . . [that come from] . . . a really good medical system . . . with periodic checkups.” One parent specifically stated that she asked about the health of the children in Korea and was “ . . . reassured . . . that the children were extremely well taken care of . . . ”

Potential health concerns were mentioned by some parents. One parent commented that her agency went “almost overboard” in preparing her for any array of health conditions, including hepatitis B, handicapping conditions, and unexpected situations. Participants also mentioned negative comments made by the media, family, and friends about health problems of adopted children. These included a report of a family member adopting a child who turned out to be a “sociopath” and news of an adoption agency bringing children to the United States who had “so many problems” that they were taken back to the country of origin.

The second category of responses, “Expectations about the types and amount of health information that would accompany the referral of a specific child,” included responses that consistently reported the belief that information would be superficial and short, unavailable, or unreliable. One parent said information is “sometimes often hard

to get . . . so I wasn't really expecting a lot." Another parent said she was told that a medical record may " . . . sound more daunting than it actually is" because reports must be negative to qualify a child to be adopted. One parent commented that "you are pretty much limited to what the circumstances are . . ." explaining further that " . . . some children are abandoned with no information." These impressions were obtained from information provided by adoption agencies and international health experts.

Responses in the third category, "An understanding that the social information about a specific child referral would be limited or unavailable," were due to the possibility that a child would have been abandoned (birth mother unknown) or that information was difficult for the agency to obtain. As one parent explained, she was not sure if the information truly was not available or if they were just afraid to say too much. Although it was unclear from this comment who "they" were and why there was a fear to "say too much," perceptions were that parents, in general, did not expect much social information to accompany the referral of a specific child.

Table 3. I. Prereferral

Question 2: In what ways were you supported by your health care provider in your efforts to obtain more information, access resources, or obtain referrals and other ways to advocate for your child's health needs?

Response Themes	Group 1	Group 2	Group 3
No response available			

No families contacted their usual health care provider or informed them of their plans to adopt internationally prior to receiving an adoption referral.

Table 4. I. Prereferral

Question 3: What other sources did you find helpful in supporting the above efforts?
(Obtain more information, access resources, or obtain referrals and other ways to advocate for your child's health needs)

Response Themes	Group 1	Group 2	Group 3
1. Adoption agency	X	X	X
2. Other adopting parents	X	X	X
3. Books	X	X	X
4. Magazine/journal articles	X	X	
5. Internet		X	

The adoption agency was listed as a helpful and supportive resource. Comments centered on parent perceptions that the agency provided the bulk of the information they received about international adoption. Agencies also referred prospective parents to books and for interviews and discussions with agency social workers. For some adopting parents their agency connected them with other adoptive parents or discussion/support groups. One parent stated, "... I felt like I was getting enough information informally." Another recounted being "hooked up" with a "mentor family" who made it "very clear to us [that] you go to this doctor and you do this and so ... I don't remember having any real concerns ..."

All three of the focus groups mentioned books on international adoption in general as being additional sources of information, but no specific titles were mentioned. Articles in magazines and journals were sources of support for participants in two groups. Specifically, one parent mentioned receiving Holt Magazine and Adoptive

Families of America (initially titled OURS) for several years prior to adopting. The Internet was also mentioned as a source of information for a participant in one group. One parent mentioned belonging to an e-mail list of parents who had adopted older children from China and mentioned that numerous lists could be accessed; however, no specific web sites were identified.

Table 5. I. Prereferral

Question 4: Which resources/information were most helpful and why?

Response Themes	Group 1	Group 2	Group 3
1. Information and support about what to expect in the process of adopting internationally was provided by parents who had previously done so.	X	X	X
2. Information and support about what to expect in the process of adopting internationally was provided by the adoption agency.	X	X	X
3. The adoption agency's positive reputation for successful adoptions.	X	X	X
4. The adoption agency had relationship/contacts with individuals who were knowledgeable about or involved with adoption in the country of origin.	X	X	X

The first category of responses to this question, "Information and support about what to expect in the process of adopting internationally provided by parents who had previously done so," included being invited to picnics and other gatherings where

prospective parents could meet and talk with families who had already adopted. The adoption agency was often the referring source. One family, who had not used an agency to adopt, however, also stated that getting together with other parents was helpful. As a result of having to use an agency to provide a home study as a part of the legal process (but not involved in the adoption itself), she met “some people, [met] with INS, and . . . got . . . to know a couple who were adopting also. That was really wonderful to have a little network . . . ”

The second category response, “Information and support about what to expect in the process of adopting internationally was provided by the agency,” was cited as being helpful because “you felt that you were getting all possible information that you were going to get that was available to get at that time.” Commenting on the helpfulness of another adoption agency, a parent stated: “They told us what to expect . . . and gave us resources.”

The third response category, “The adoption agency’s positive reputation for successful adoptions,” was cited by several parents. One parent described her negative experience with another agency as causing she and her husband to have “our hearts broken over and over” when a referral for a child did not result in an adoption. Another parent commented that because the agency was “so established . . . and had done this for so long, they knew what people wanted to know.” Crediting a local adoption agency, one parent said: “It was [the agency] presence in the community that caused us to even start thinking about adoption . . . I started running into women in the grocery store with these little [ethnic] babies in their care and we were having infertility problems and I was going ‘Where did you get that baby?’”

The fourth response category, “The agency had relationships/contacts with individuals who were knowledgeable about or were involved in the process of adoption in the country of origin,” was cited by one family as being especially comforting because the agency used was, “very connected . . . They knew the people, they knew the doctors, [they had] lived there and helped them set this [adoption system] up . . . ” As a result, this parent felt that whatever information the agency provided could be trusted. Another parent said, “Our agency was very good . . . telling us what we could expect and what we couldn’t expect. They knew the conditions in the orphanages . . . ”

Table 6. II. Referral to Placement

Question 1: What kinds of health information did you receive during the adoption process?

Response Themes	Group 1	Group 2	Group 3
<u>At Referral</u>			
1. Birth information	X	X	X
2. Age	X	X	X
3. Growth information	X	X	X
4. Development	X	X	X
5. Photographs of child	X	X	X
6. Videos of child	X	X	
7. Social information	X	X	X
8. Physical conditions/diagnoses	X	X	X
<u>At Placement</u>			
1. Healthier than expected	X	X	
2. Unexpected situations/new information	X	X	X

Two of the three focus groups mentioned receiving some kind of birth information, including where the baby was born (e.g., home, hospital), premature births (prematurity ranged from 1-2 months), and extended hospital stays. One mother

surmised from reading the medical report that the birth must have been “a difficult delivery.” All three groups mentioned receiving information about their child’s age at the time of the referral. Growth information was limited to weight although one parent did mention receiving a [head] circumference measurement and another said she received information about the child’s length. One mother said, “We were given some medical information on a piece of paper that showed he was very, very small.”

Some level of development was also received by parents at the time of the adoption referral. One mother, commenting on the development of the child referred to her (and subsequently adopted), said that “he was very developmentally delayed as we expected.” Another referral specifically mentioned achievement of developmental milestones: “He walked at this age, he smiled at this age.”

Receipt of photographs were mentioned in all of the groups although one mother was given a different child than the one featured in the photo once in the country of origin. Videos were mentioned as being received in all three focus groups. One parent received three videos; she claimed one was “useless” because the child sat on the caretaker’s lap crying and screaming. Another video sent two weeks later was of the same child, but who that time smiled and demonstrated fine motor skills. A third video was obtained by friends who were also adopting from the same orphanage. The advantages to that film were that it showed the child receiving a toy sent from his prospective parents and also showed him with peers which gave the parents an opportunity to compare his small size with others in the same setting. Another parent reported that the video she received did not correlate with the written medical record

which “sounded really scary . . . We looked at the video, he is moving around . . . Just looking at the video we knew that it didn’t match up” [to the medical record].

Social information varied in the amount and type of information received. Several parents mentioned meeting the foster care mothers once in the child’s birth country. Additional social information was obtained from them at that time. One parent received an envelope that contained the birth mother’s name and address, but was not allowed to open it until after the court date for adoption within the country of origin. A parent who did not receive much social information stated, “We just assumed that was the chance you take and part of the adoption process. We weren’t going to push it too much.” One family, however, was “amazed at how much we got. We even have the story, you might say, behind our son’s conception.”

All of the focus groups mentioned receiving information about the child’s health, including specific diagnoses in many instances. These included “superficial, cosmetic” diagnoses of mongolian spots and other body marks, congenital conditions, such as polydactylism, cardiac conditions (unspecified), and a hearing deficit, illnesses such as bronchitis, frequent colds, “stomach problems,” and cases of hospitalization.

Two of the three focus groups had respondents that perceived their child as healthier than expected when they first saw them. One parent was expecting her child to be “fragile” because he had been so premature but, instead, looked healthy. Each of the three focus groups reported finding themselves in an unexpected situation of receiving new information once in their child’s birth country. One mother was given a different child than the one who appeared in the photo and medical dossier she was sent. Another

mother was made to return to court a second day in order to sign “extra papers” acknowledging that “I was aware of this and this and this . . . ” after being “just grilled . . . about why I wanted to adopt this child.” Still, another mother reported that at the time of the medical referral she had been informed that her child weighed 7 pounds at birth. Once in the child’s birth country, however, she was told that “everybody’s baby was 7 pounds. I think they had no idea.”

Table 7. II. Referral - Placement

Question 2. In what ways were you supported by your health care provider in your efforts to obtain more information, access resources, or obtain referrals and other ways to advocate for your child’s health needs?

Response Themes	Group 1	Group 2	Group 3
Health care provider supported parents’ efforts to:			
1. Obtain more information.	X		
2. Provide resources.		X	
3. Obtain referrals.			
4. Find other ways to advocate for the child.	X	X	X

Physicians were contacted by some parents, but not all, once a referral was received. Recommendations were made to some parents to obtain more information about the child referred to them. One mother said she was given this advice after her physician watched the video tape she had received.

One family contacted a nurse for information. As it turns out, this was the only study participant who mentioned being provided with additional information, including

journal articles. No health care providers were mentioned as making referrals for the parents prior to adopting or for the child's care afterward at this stage of the adoption process.

Although parents stated that they had already decided to adopt the child referred to them before contacting a health care provider, the ones who shared the medical record with a physician admitted that they did so for peace of mind. They wanted to have a medical opinion about the health of the child referred to them, as well as information about what to expect in terms of frequency of medical visits once the child was in the United States. All health care professionals who were contacted provided appointments, reviewed medical information, and made health assessments when requested to do so by prospective parents. One parent said that her preadoption consultation visit, which lasted approximately 30 minutes, was free.

Feeling confident that a health care provider was competent to meet the health care needs of internationally-adopted children was viewed as important. One parent, who interviewed physicians but did not share information about her specific child referral, found that all of the physicians she spoke to had some international adoption experience and, specifically, knowledge about hepatitis B.

A parent brought his child's paperwork to the local physician only to discover that the doctor was an adoptive parent with two internationally-adopted children and that the nurse who assisted him also had two adopted children. As a result, the father felt they were supportive of adopting. Another family, however, had approached their usual health care provider for antibiotics to take on their trip to adopt their child, only to be refused. Another physician in the same practice had Third World experience and agreed

to provide the antibiotic. The parents believe this was because he understood and was supportive of the need for it, based on his international experience.

Table 8. II. Referral to Placement

Question 3: What other sources did you find helpful in supporting the above efforts?
(Obtain more information, access resources, obtain referrals, advocate for your child's health needs)

Response Themes	Group 1	Group 2	Group 3
1. Adoption agency.	X	X	X
2. Health specialists.	X	X	X
3. Contacts in country of adoption origin.	X	X	
4. Local translators.	X		
5. Family member.			X

The adoption agency was mentioned as a source of support in the II. Referral to Placement time period. All three focus groups mentioned they felt comfortable with their agency not pressuring them to take a specific referral. "They were preparing us. You may get a referral that you don't feel good about or something like that and it's your choice. If that's not the best family for that baby then fine . . ." one agency representative was reported as telling a family. Parents also felt positive about agencies that made attempts to get additional information for them when requested.

Specialists considered as helpful sources for additional information included international health experts. One mother said she did not even contact a local doctor but instead contacted international adoption specialists who were familiar with the particular

orphanage from where a child was being adopted. These specialists' names "kept surfacing either through the Internet chat rooms or through . . . our agency" reported one parent. One mother admitted calling every one of the international adoption health specialists for whom she was given a name and number. She said: "They gave us a list of questions . . . they told us their experience [in that country] . . . They gave us the ramifications [of the information we had] . . . they faxed [questions] to that country and they got the information." Other health care specialists consulted by parents included physicians who specialized in infectious diseases, genetics, and neonatology. Non-physician contacts included an obstetrical nurse, social worker, and friends who worked with the handicapped.

For some families contacts in the country from which their child was being adopted were helpful resources. Friends were the foster care parents for one family who adopted internationally. For another family friends in the country of origin were able to provide updated information about the deteriorating health of a prospective adoptee, which was instrumental in the parents' declining that referral. Several parents commented on foster care mothers providing additional information about the child they were adopting. One parent admitted to "bribing" a police officer in order to obtain photographs of her children's birth mother. Another parent stated that a physician at the orphanage where she adopted her child was able to give her additional health information about that child because they coincidentally both spoke the same second language.

The sister of one mother who was adopting internationally accompanied her to her child's birth country. Coincidentally also an adoptive mother, she was considered invaluable in teaching the sister (and other adopting parents) general parenting skills.

Finally, one parent mentioned the owners of an ethnic restaurant in town [United States] as translators for the medical records she received. Although she laughed when she compared her resources with others in the group, she admitted that the translations confirmed what the agency had told her was contained in the medical report and that having that information in itself was enough for her to proceed with the adoption of her daughter.

Table 9. II. Referral - Placement

Question 4: Which resources/information were most helpful and why?

Response Themes	Group 1	Group 2	Group 3
1. Experienced agency that was successful in placing children and knowledgeable about what to expect in terms of adopting from a specific country.	X	X	
2. Family member			X

The first response theme, “Experienced agency that was successful in placing children” was explained by one parent, who was especially pleased with the amount of information he received from the agency medical report. “I think just dealing with the agency that we did . . . they could tell you so much of their track record and what had happened with other people . . .”

The second theme “Family member” was mentioned as the most helpful by the one parent whose sister accompanied her and provided child care information in the country of origin.

Table 10. III. Postplacement

Question 1: What kinds of health information did you receive after adopting?

Response Themes	Group 1	Group 2	Group 3
Specific medical diagnoses/health issues	X	X	X

The response category, "Specific medical diagnoses/health issues," included comments about immunizations, ranging from the physician in the United States continuing the series of vaccinations that was begun in the country of origin, to another totally disregarding them and starting the series over. Specific diagnoses noted postplacement ranged from "healthy" to having problems with eyes, teeth, gait, posture, nutrition, allergies, skin lesions, chronic ear infections, and a hearing deficit. Developmental delay and malnutrition concerns were also noted. One mother suspected that her child had an orthopedic problem but was convinced after seeking the opinion of three physicians that he did not.

A child who was ill when placed with the adoptive parents was still ill at entry into the United States, however, despite starting antibiotics in her birth country. The parent did not specify the illness but had been reassured by her local health care provider once in the United States that the child would get well on the antibiotics. Another parent commented on her child's development of a viral illness that had neurological sequella. However, the illness occurred months after being in the United States and was not associated with the country of origin or being adopted.

Table 11. III. Postplacement

Question 2: In what ways were you supported by your health care provider in your efforts to obtain more information, access resources, or obtain referrals and other ways to advocate for your child's health needs?

Response Themes	Group 1	Group 2	Group 3
Health care provider supported parents' efforts to:			
1. Obtain more information.			
2. Provide resources or assisted in accessing them.			
3. Obtain referrals.	X	X	X
4. Find other ways to advocate for the child.	X	X	X

Once in the adoptive home, health care providers were not mentioned as being helpful for obtaining more information or accessing resources. When parents made requests for referrals, some health care providers were helpful. One parent said: "He [the physician] was really great with it. I didn't feel like he begrudged us the path or finding out anything . . . He was really great about giving the referral."

When parents accessed information, resources, and referrals on their own, physicians were supportive of their efforts. One parent said: "They were always excited for us and the health stuff that I learned . . ." Another mother said that when they mentioned resources they had accessed on their own, the physician responded, "Oh yeah, I'm glad you're doing that. It hadn't been recommended by him . . . [but] he was very supportive of it." Another added: "The pediatrician said 'ok, go ahead and do it

[referral] . . . as long as I know exactly what is happening. You have to keep me informed of what you are doing because my job is to make sure that he is healthy.’ ”

Receiving competent care when parents accessed physicians on behalf of their children was categorized as a way of showing support. One adoptive parent said that, based on the referral information they had received, they were not concerned about the health of the child they had adopted. Nonetheless, they made an appointment with their local health care provider who “was impressed with their medical records . . . said this is good information . . . they have done a good job . . . It went real well.” Another, who was concerned about her child’s development, was assured that the specific problem would resolve within weeks.

Some parents definitely felt that their health care provider was emotionally supportive which was also categorized as a way of providing support other than through obtaining information or accessing resources. One mother, who felt she was perhaps over-reacting by suspecting a heart problem because her child complained of “heart pain” was reassured by her physician and was encouraged to bring the child in for “peace of mind.” At another visit the mother states that her child’s physician “. . . wasn’t an alarmist. He quelled a lot of our anxiety with a sick baby that we knew nothing about. He was terrific.”

Several parents mentioned the physicians they contacted as focusing more on the parent/child bonding rather than medical concerns of the child. A physician had encouraged a parent not worry about a physical problem but, instead, focused on bonding with her child, saying: “He . . . just needs you.” The mother added: “I was basically just thinking . . . ‘ok, see how my child is physically’ and he just kept going back to the social

part . . . he would be talking to [the child] and asking him questions . . . it made me feel like he cared for my son, which is important when you are just a new mom.”

Table 12. III. Postplacement

Question 3: What other sources did you find helpful in supporting the above efforts?
(Obtain more information, access resources, obtain referrals, or other ways to advocate for your child’s health needs)

Response Themes	Group 1	Group 2	Group 3
1. Health specialists	X	X	X
2. Community resources	X	X	
3. Books, adoption magazines	X	X	X
4. Internet		X	
5. Support groups		X	
6. Adoption agency			X
7. Culture camps		X	X

Physician specialists that were found to be helpful included: international adoption health experts, ophthalmologist, orthopedist, allergist, ear, nose and throat specialist (ENT), dermatologist, and dentist. Community resources that were identified as being utilized and supportive postplacement included Family Outreach, the local infant evaluation clinic, gymnastics and swimming programs, Eagle Mount skiing and horseback riding, physical and occupational therapists, and a special education program. “Hearts and Homes,” a support resource for adoptive and foster care parents in Bozeman, had also been discovered and utilized by some parents. Additionally, Internet resources, adoption magazines that focused on specific countries from which children had been

adopted, and support groups provided information for parents and were accessed once the adopted child was brought to the United States.

Families also discovered books that were helpful and included general books on child development and books specific to health issues of concern. A parent listed "the phone book" as a resource for self-referrals to physician specialists. One family also accessed international adoption health experts to explain possible causes for a health problem. For one family who contacted international adoption health experts, a referral was made to their community's "Family Outreach" services, an organization they had not been aware of before. This referral, in turn, resulted in the parents accessing other community resources such as physical and occupational therapists.

In one instance the adoption agency that referred a child for placement was listed as a helpful source. Although not utilized, the agency had offered to try to get additional information about a child's background to determine if it could have a bearing on an illness the child developed months after adoption. Finally, two of the three groups mentioned culture camps as helpful resources in keeping a link between the child's birth country culture and American culture.

Table 13. III. Postplacement

Question 4: What resources/information were most helpful and why?

Response Themes	Group 1	Group 2	Group 3
1. Health specialists (including international adoption health experts)	X		
2. Other parents	X		X
3. Internet		X	

In one group a mother credited an international adoption health expert for providing “all my resources that really helped.” Another mother, concerned that her child had an orthopedic problem, accessed three different physicians on her own before she was convinced that her son was normal.

Other parents were listed as most helpful at this stage of the adoption process. For one parent, advice came from another parent who had not adopted, but whose child had similar health symptoms. “A friend of mine, her son has a lot of allergies and she was telling me that before they diagnosed it he was eight years old and cried a lot . . . once they were able to pinpoint his allergies . . . it was like he was a different boy, just like that.” This parent’s anecdotal information provided support for the parent who then continued to pursue an allergist for his child’s problems, which were eventually diagnosed as allergies. Commenting on other adoptive parents as being especially helpful, one parent explained: “There was a group of parents that must have adopted the

same time as us, within a year or two, so we all had similar age children and we ended making a little mother's group that met at [restaurant] once a month . . . just to get together kind of informally."

The Internet was also listed as an especially helpful resource and a means by which to have contact with other adoptive families. One parent summed up the advantages.

The Internet is a real valuable source because it seems like . . . there are so many lists . . . I belong to an e-mail list of parents who have adopted older children from [country] and there are numerous lists like that for different countries and it is just parents conversing with each other by e-mail. You can throw a question out there and get 20 e-mails in response . . . it is a pretty valuable source [for] bouncing things off of people and finding some helpful information.

Table 14. IV. Advice

Question 5: If you were going to adopt again or give advice to prospective adopting parents, what information would you insist they access? What other advice would you offer?

Response Themes	Group 1	Group 2	Group 3
1. Get a reputable agency, especially one that specializes in the country you plan to adopt from.	X	X	X
2. Talk with other adoptive parents, support groups, chat rooms on the Internet.	X	X	X
3. Use health care providers with international health experience.	X	X	
4. Use all the resources you can find or are told about, not just one source.	X	X	
5. Learn about international adoption: books, Internet, adoption magazines.	X	X	
6. Take another person not emotionally involved with you when you first meet your child.		X	
7. Do not look at the adoption picture until you've decided to adopt; you will bond to the child at that point.	X		
8. After you adopt, help others doing so.	X		
<u>Other Parent Comments</u>			
1. Sometimes it's better not to know too much.		X	
2. You are your own and best advocate.	X	X	

Parents had many words of advice for prospective adopting families. Having a reputable agency was voiced as a real asset in all three groups. This included researching the agency, getting referrals, and having an agency that specialized in adopting from a specific country. Contacting other adoptive parents was equally seen as an asset. Health care providers who had experience with international health concerns were named by all three groups, with two groups specifying the use of international adoption health experts. One parent, who had not used an international adoption health expert, stated:

I would also do what [name] said [use international adoption health experts]. These names she mentioned were all familiar to me when I was going through the process, but I didn't feel comfortable contacting them. I guess I kind of felt like I'm just one of thousands of people . . . to them—you're right—everybody is important. My suggestion would be--don't be afraid . . .

However, parents were quick to point out that they did not recommend using one source of information, insisting that prospective adopters use every and any source made available to them. In doing so, parents encouraged prospective adopting parents to learn about international adoption in general, especially by reading and communicating on the Internet with other parents who had adopted. One parent said, "I have gotten so much information just on books for kids to read . . . [and] getting that magazine is incredible . . ." Another said: ". . . the [adoption] scene is constantly changing. I can't believe how different things look now and the whole international adoption scene than when we were doing it. The countries change and the climates change . . ."

On a more personal note, one parent mentioned that emotions can sometimes interfere with obtaining information. For her this involved returning to her child's orphanage and being so overwhelmed with the responses of former caretakers to her child's return that she forgot to ask the written questions she had brought. Another

parent said that if she had not been forewarned, she would never have thought to have a friend accompany her to the airport to take pictures when her child arrived.

One group was quite adamant that parents should not look at the photo of a child and still think they could be objective about deciding to accept the referral or not because bonding would have already taken place. As one parent said: "They should not give a picture in my opinion, because you are going to love whichever kid they hand you anyway. So, if you are bonding with a part of that, then you get somebody totally different, it's shocking." Another said: "There is the picture . . . there is the medical . . . it's like whenever you get those papers it is already your child even if you don't like it, it's already your child." One parent, who was trying to decide whether or not to accept the referral of a child, said, "You can look at the picture and let yourself fall in love with it."

Providing information and support to other parents who are adopting was viewed as something parents could do once they had gone through the adoption process themselves. One parent intimated that she felt this was something she could have used in the adoption process. "I think a support group would have been great . . . to have somebody to call and say, 'Did you have this?' or 'What do you think about that?'" Another parent said, "Talking to other people was the most reassuring."

Other comments included the suggestion that perhaps there is no real need to have information ahead of time. In one parent's circumstance, she had been given information about a child, but not the one that was placed with her. Another commented, "We had just an awful experience . . . it was just horrible and had we known what we were going to go through, we may not have done it."

Parents viewed themselves as the best advocate for themselves and their children and encouraged prospective adopters to remember that when adopting. Parent comments about this sentiment included “not just to take one answer or one resource” when seeking information. Another recommended for parents to “be aggressive” and more than one adoptive parent emphasized that it is the parent who is “responsible for getting your own information.”

Phase II: Data Interpretation

In Phase II responses to the focus group questions were analyzed separately for meaning, consistency with findings in the literature, and new and unexpected information. In this phase of interpreting the data, each focus group was examined for appropriateness in meeting the objectives of this project. The fifth question, which was in two parts, asked: “If you were going to adopt again or give advice to prospective adopting parents, what information would you insist they access? What other advice would you offer?” This question was not categorized into different time periods of the adoption process because it was asked as a general question, not specifying a particular time in the adoption process. Finally, focus group responses were analyzed to determine the applicability of using Kohnke’s advocacy model for this specific population.

Question Analysis

Question 1 asked, “What kinds of health information did you receive (before, during, and after adoption)?” Information is important in advocacy because it provides the basis upon which decisions are made. In the first phase, I-Prereferral, most

prospective parents knew whether to expect a child from a foster care home or orphanage. They were also aware that specific aspects of a child's health and social information would be scarce if available at all. These findings coincide with the literature that indicates predominantly foster-care settings for children adopted from some countries (e.g., Korea) and orphanage settings for other countries (e.g., Russia, China, Romania). The literature also indicates that preadoption information is often sketchy (Johnson, 1997; Jenista, 1993).

In the second time frame, II. Referral to Placement, parents had received specific information about their children. Information varied, however, depending on the child's birth country. All three focus groups received basic data information such as age, growth, and development although information seemed to be more detailed with Korean adoptees than others. Again, this coincides with the literature (Johnson, 1997; Jenista, 1993). The additional information parents adopting from Korea received was considered by them to be "superficial, cosmetic" information such as descriptions and photographs of birth marks.

Most of the time parents were provided more information when they requested it, however, in some cases the usefulness and reliability of the information was questionable. For example, a parent whose child had a head sonogram in her birth country was told by the reviewing physician, "Yes, I think I see something." The parent felt that perhaps her child was actually normal but that the physician felt pressured to make some kind of diagnosis in order to qualify the child as adoptable by that country's standards. This also coincides with findings in the literature (Jenista, 1999d; Mitchell &

Jenista, 1997). Knowledge that information may not be reliable was an important factor to consider when making a decision whether to adopt a specific child or not.

All parents in this project mentioned receiving a photograph prior to adoption. For many this piece of personal information started the bonding process for the parent. This information has been noted anecdotally (Johnson & Hostetter, 1996). In addition, Smith and Sherwen (1983) found in their study on bonding that parents' first meeting with their adopted child was important in attachment later.

For children who were not abandoned, more social information was received than anticipated. This was partly due to obtaining more information in the child's birth country. This suggests parents are not always provided with information initially, but it may be available if pursued. The reliability of information provided by the agencies was also questioned when new information was given to parents.

One parent was asked at her embassy interview if she was aware that her child's birth mother had an incurable disease. Because the information was in the written records, the parent felt that the agency knew about this information but for some reason had not shared it with her. The question, then, is whether information is actually not available or simply not provided in some instances.

Postplacement information centered on diagnoses of medical conditions made by health care providers, which in some cases did not agree with parental concerns, which coincides with the literature (Jenista, 1986). Some parents sought additional information and assessments from specialists. No mention was made or information provided about the negative effects of institutionalization, although more than one-fourth of the children

were adopted from orphanage settings. Some parents did mention that bonding issues were addressed, however, no information was provided to assist parents in this area.

Question 2 asked: "In what ways were you supported by your health care provider in your efforts to obtain more information, access resources, or obtain referrals and other ways to advocate for your child's health needs?" In advocating for clients and their families, identification and access to resources is crucial. However, no study participants contacted a health care provider before receiving a specific child referral. In addition, parents in this study rarely made a visit to their usual health care provider once a referral was received. Instead, they opted to contact international adoption health experts or other specialists. This may be the result of families being warned that information would not always be reliable or because parents suspected that their usual health care provider, not accustomed to seeing institutionalized children, would not be competent to identify problems. These sentiments coincide with findings in the literature (Jenista, 1999b).

Parents also said they had already made the decision to adopt and sensed that the medical report was so negative that their health care provider might try to dissuade them from adopting a specific child. Thus, the parents did not share the medical referral information with the health care provider who would be caring for their child. This suggests what parents admitted--they had already begun to bond with the child they planned to adopt prior to ever meeting the child. These reactions suggest that parents felt they were responsible for the decision whether or not to adopt a specific child, and that once the decision was made to adopt a child, the decision was also made to accept whatever health issues accompanied them.

When taking their child to the health care provider postplacement, parents were divided in their level of confidence with their health care provider. Some parents expressed feeling confident in taking their child to a specific health care provider because they were not expecting anything but a “healthy” diagnosis. Others who had concerns about their child, however, expressed dissatisfaction with their health care provider’s knowledge about international adoption health issues and physicians that did not seem to take parental concerns seriously.

This can be explained in several ways. First, the literature describes Korean adoptees as having considerably fewer health problems than other adoptees and that their adoption referrals usually are accompanied by comprehensive and complete medical records (Johnson, 1997; Jenista, 1993). More than half of the respondents in this project had adopted from Korea and had not had any concerns about the health of their child which may explain why the use of local health care providers was viewed as satisfactory. However, many parents adopting from other countries were not satisfied with the care they received from their health care provider. They felt their concerns were not addressed, and in some instances, diagnoses were not made. This coincides with literature about parent perceptions (Jenista, 1999a) and studies that indicate physicians often miss diagnoses or mis-diagnose internationally-adopted children (Hostetter et al., 1991).

The responses in this project also suggest that parents considered any deviance from the expected norm to be a concern that needed intervention. It also suggests that parents felt an urgency to intervene and wanted answers to their questions and concerns. This differs from the study by Edwards (1987) which showed adoptive parents not

perceiving any more needs than biologic parents. However, Edward's study did not consider initial health issue concerns.

Although health specialists often provided diagnostic information for parents, it was perceived that their attitudes toward parental concerns was far from supportive. This may be due to specialists' lack of knowledge about health issues related to international adoptees as well as the parent's self referral being viewed as "overreacting" which parents sometimes felt was the case. Parents admitted that their persistence often resulted in testing being done or referrals being made. The literature supports parent impressions that health care providers are often not aware of the effects of institutionalization and miss diagnoses (Hostetter et al, 1991), and that children may benefit from early interventions to address concerns (Johnson & Dole, 1999).

Health care providers did not provide or suggest information for parents that would explain the reasons for some of the health concerns or how to manage them other than to "wait and see." Resources were only provided by one health care provider (a nurse) based on parental concerns about a specific health issue. Referrals were never mentioned as being offered by health care providers even when there were parental concerns. Referrals were made, however, when parents specifically asked for them. When referrals were not made, parents opted to access them on their own. This suggests that health care providers did not assess problems in areas parents identified, which coincides with the literature (Jenista, 1986). Another reason may be that health care providers were not knowledgeable about community resources that could assist families with their concerns.

The health care providers that were seen as most supportive in other ways were those who seemed competent and caring. Although one parent did not agree with the assessment her pediatrician provided and sought out specialists for other opinions, she did feel that the physician cared for her and her son and was interested in them. Other parents, however, not only expressed dissatisfaction with the care they received but also felt their concerns were not taken seriously. These parents opted not to return to those health care providers.

The third question asked, "What other sources did you find helpful in supporting the above? (obtain more information, access resources, or obtain referrals and other ways to advocate for your child's health needs)." Responses identified numerous sources in addition to health care providers in all time frames of the adoption process. This coincides with the study done by Jenista (1986) that indicated families do not have one source for information.

The fourth question asked, "Which resources/information were most helpful and why." Responses indicated that information and resources were predominantly from adoption agencies and other parents. This suggests the importance of having a reputable agency that is knowledgeable about conditions in the country from which parents are adopting and successful at placing children with families and the importance of parental confidence and trust in the information provided. Parents also seemed to have more confidence in health care providers that had Third World experience and were often referred to these health care providers by the adoption agencies.

Other parents were repeatedly mentioned as important resources. This emphasizes the need for adopting parents to have firsthand information as well as to be

supported by others who understand the issues they are facing. This may explain why some parents opted to seek out the advice of other adoptive parents rather than health care providers when there were concerns. One mother said she used her health care provider last because “most of the problems were parenting issues anyway.”

Advice by parents, provided in response to the fifth question supported the responses given in previous questions. The two-part question asked: “If you were going to adopt again or give advice to prospective adopting parents, what information would you insist they access? What other advice would you offer?” Recommendations included finding a reputable agency, using a variety of resources, and reliance on oneself to get the information needed. Although a variety of sources for information were provided, adopting parents emphasized that the responsibility to advocate for one’s child ultimately rests with the parents.

Application of the Conceptual Framework: Advocacy

Advocacy, defined by Webster as “to write or speak in favor of or support” (Webster’s Dictionary, 1997, p. 7), was the conceptual framework for this study. The “information and support” category of Kohnke’s (1982) advocacy model was used as the framework foundation. Informing and supporting involve: (a) a desire to provide information for a client, (b) a client who desires to have the information, (c) being aware of others who do not want information shared with a client, (d) accurate information presented in a way that is significant to the client, and (e) providing information so clients can make an informed decision that is in their best interests and meets their needs.

A Desire to Provide Information for a Client. The data from this project indicates that adopting parents had a variety of sources from which to obtain information. The two main sources for information were the adoption agency and other parents. Local health care providers did not seem to be knowledgeable about or aware of the needs of families adopting internationally. Parents expressed frustration with a “wait and see” attitude in response to their concerns and would have liked additional information and/or resources, referrals to specialists, and an understanding of the needs of families to have their concerns addressed.

International adoption health experts who were contacted were viewed as providing helpful information, resources, referrals, and emotional support. One parent commented that her husband balked at proceeding with an adoption, and they called an international adoption health expert for advice late in the night. Not only was the expert accessible, but she provided emotional support and was available to the parents for further consultation once they arrived in the child’s birth country. Other kinds of specialists (e.g., dermatologists, allergists) provided requested assessments, but parents felt they had to be persistent in getting them to do the assessments and additional testing. Adoption agencies, other parents, and international adoption health experts were viewed as advocating for parents by serving as sources of information and support.

A Client Who Desires to Have the Information. Advocacy also involves having a client who desires to have the information. Information is a necessity for informed consent, although parents were clear that health information was not a major consideration in whether or not to adopt a child. Bonding with the photograph and

accepting a referral when it was offered involved “a leap of faith” for some. Some parents admitted that they did not share information with their health care provider because they did not want to be dissuaded from accepting an adoption referral they had already decided upon. Parents did not make prereferral visits to health care providers in any of the focus groups.

International adoption health experts and other experts (e.g., neonatologist, geneticist) were contacted for an assessment of specific health concerns, however, parents usually accepted the adoption referral despite negative assessments. This suggests some health care providers were not given the opportunity to advocate for adopting parents because some parents did not desire to have information.

Being Aware of Others Who Do Not Want Information Shared With a Client.

When advocating for clients, it is important that there is an awareness of others not wanting to share information. Parents were aware that sometimes information would not be available, was unreliable, or was sketchy at best. Responses from the focus group interactions suggest this was something parents accepted as a part of the adoption process but it was also an area in which parents had no control. Some believed that information was often not available or that the agency simply could not access it. One parent adopting from Korea acknowledged that sometimes social information could be obtained for an additional price. It is not known to what extent agencies attempt to obtain information for parents. If agencies are making an effort to obtain information, this alone would be advocating for adopting families. However, if no sincere attempts are made, the agencies are not advocating for families in this area.

Accurate Information Presented in a Way That Is Significant to the Client. When advocating for clients, it is important that information provided is accurate and presented in a way that is significant to the client. Parents accepted that information was not always available, was incomplete, and often unreliable. However, they did not expect to be deliberately deceived. Some parents felt this had occurred when they were given incorrect information despite availability of the correct information. One parent had taken pictures of the foster care home she was told her child had been raised in, only to meet someone on the street who recognized her child, called him by name, and informed her that the information she had received was incorrect. Another parent believed her adoption agency had to know about the health problems of her child's birth mother because the information was in the file at the United States Embassy. Although warned about the potential to receive inaccurate information, these kinds of responses indicate visits to the adopted child's birth country often provided new, reliable information. Some parents who had not traveled to their child's birth country expressed some remorse at not doing so, believing they may have obtained additional information. If this information was accurate, it could be viewed as a means by which to advocate for one's child.

Providing Information So Clients Can Make an Informed Decision That is in Their Best Interests and Meets Their Needs. The purpose for providing informed consent is so that clients can make an informed decision that is in their best interests. Parents listed adoption agencies that were successful in placing children with families as knowledgeable. Parents in this study also advised prospective adopting families to seek

out reputable agencies with these characteristics. Having relationships with others who were knowledgeable about conditions in the country of origin were also important sources of information and support.

One of the more common comments parents made was that they felt prepared to adopt. This kind of experience indicates that parents felt that they had received enough, appropriate information as well as support from their agencies to make a decision whether or not to accept an adoption referral. Even those parents who adopted children with health concerns felt that they had been provided enough information upon which to make a decision whether or not to adopt. The one parent who admitted declining a referral, initially had accepted a child with an unknown cardiac condition. She only declined the referral when a friend in the child's birth country provided additional information that suggested the child would not survive. Other parents who had adopted children with health concerns were generally aware that concerns existed even though they were not sure of the exact diagnoses.

The families felt that they had been adequately prepared for the adoption process and issues related to a specific adoption referral, allowing them to feel comfortable with the decisions they made. This indicates they had been provided the necessary information for informed consent. In doing so, the families had made their own decisions--an important component to advocacy.

Conclusions

This study showed similar results to those found in the literature. Conclusions from this project included:

1. Parents receive incomplete health information before, during, and after the adoption process. In this study parents said they had been forewarned not to expect much.
2. Many health care providers are unaware of or do not make referrals to community resources that could assist families.
3. There is no one source for health information for adopting families.
4. Adoptive parents are creative and persistent in finding ways to advocate for their children.

Prestudy Assumptions

Several assumptions made by the researcher were implied by the focus of this study. Questions were asked which included:

1. Parents had impressions about adoption prior to receiving information as a part of the adoption process.
2. Adopting parents desire to be fully informed about expectations in the adoption process.
3. Health care providers, including specialists, are a main source of information and support for adopting families.
4. Parents will receive health care from their usual health care provider for their internationally-adopted child.

One assumption that was confirmed by this study was that parents had impressions about adoption prior to receiving information as a part of the adoption process. For some parents there was the impression that a negative image of adoption still existed although they did not seem to agree with that image. One parent said: "Everybody was shocked that we were going to do this [adopt] because all you heard was 'adoption has a bad press right now.' I think it is getting better . . ."

Another parent said:

People say things when they find out you are adopting, 'Oh, I hope it turns out okay. I know somebody who adopted, and when their kid got to be a teenager, he was a mass murderer.' Well, nothing is guaranteed in life. You take what you're given and you work with it and when something comes up, you see what you can do about it.

The other assumptions held by this researcher at the start of this study, however, were unfounded in this study. First, it was assumed that being fully informed about a child referral was both expected and desired by adopting parents. For this reason the focus of this project was on the health information adoptive parents received at various times in the adoption process. As it turns out, although parents seemed to be interested in receiving more social information, a general theme from the data was that this was not expected. Additionally, parents did not expect to receive much health information. This may be why some parents expressed satisfaction with the amount of health information they received even when it was far from complete.

When asked in question 1 "What kinds of health information did you receive?", one parent said: "We got . . . information . . . not a lot . . . and I can't say I had a desire to have a lot more because I think at the time we were both naive regarding international adoption and things can occur . . . we were happy with the information that we got."

Another parent said: "We were just so glad to finally get a referral at that point it [the medical report] didn't matter," and another said: "It was like, "okay, this is our child and we are going to deal with it and in a way it's almost scary to have so much information."

A second assumption was that health care providers, including specialists, were a main source of health information and support for adopting parents at all steps in the adopting process. With this assumption in mind, the second question "In what ways was your health care provider supportive . . ." was asked. Although some parents did find contacting their health care provider to be useful or supportive, question 2 did not consider that adopting parents might not consider their health care provider as a source of information or support prior to receiving an adoption referral. As it turned out, no study participants mentioned seeking a prereferral visit with a health care provider. When asked reasons for not doing so, one parent responded:

I think if I had adopted from somewhere besides South Korea at that time I would have checked a lot more, but . . . once you went through their [agency] workshops and they told you what they know . . . about how they only pretty much let you adopt well babies . . . I didn't really feel like you had to go and get a lot of other information unless something just happened to come through on your developmental reports or something. . . .

Another parent said, "I think maybe some of us live our lives more dangerously. It didn't occur to me to get any more information."

Once a child referral was received, some parents opted not to contact their health care provider. For some parents the decision to adopt had already been made. One parent, concerned that the physician might try to change her mind about adopting a specific child, purposely did not seek medical advice. "I looked at this [medical report] and thought, "Oh my gosh, I know my doctor is going to say 'This is too scary.' He was

such a little doll. It was like this is going to be really hard to turn . . . down. I can't imagine we would get one [referral] this good again."

Another parent voiced concern that "a local doctor" would not have the experience "to read a report like this . . . [they don't have] enough knowledge and not enough experience with internationally-adopted children." Another parent did not contact their health care provider with referral papers because he was not anticipating any problems. "Our first child was to term . . . and everything looked really good with him and he has been fine [so] I didn't go to a doctor before he got here." Another parent said, "It didn't occur to me to check to take a picture into my pediatrician."

Question 2 also did not consider that some encounters with health care providers postplacement would be negative. Several families expressed frustration that their health care provider did not take their concerns seriously. A parent whose child developed eczema described her physician's response to her concerns as "It was just kind of brushed off, 'oh, it's just reactions and it could be emotional.' " Another said: "He [the physician] did a basic screening just fine. He is more the type that just says 'he'll outgrow it, we'll wait and see . . . ' [which is] why we went ahead and got the referrals on our own." Concerned about his son's allergy symptoms, one father said: "I kind of felt there was that shortcoming in our care with our son with the pediatrician because I felt he had allergies . . . I didn't feel that the pediatrician was really up on that so I took him to a dermatologist . . . "

There is no data from this study that mentions negative encounters with specialists in response to question 3, "What other sources did you find helpful . . . " because the question only asked for positive experiences. Describing his encounter with

a dermatologist, a father said: "Even there the information wasn't that great, so I just did it on my own, taking him totally off of dairy . . . products for the first two years of his life." Another parent was told by a pediatric allergist, "I don't normally test children this young" but was persuaded to test the child after all when the parent explained: "We have no medical history and this child is having difficulty and I want him tested . . . if he screams, we'll quit."

The third assumption that parents would continue to receive health care from their usual health care provider for their internationally-adopted child. Some parents indicated just the opposite. One parent described receiving negative reactions from a health care professional, who happened to also be a family member, about an adoption referral she and her husband were seriously considering. The couple decided not to accept the referral not only because the professional advised against it but because the advice was so negative and emotionally-charged. They also decided not to consult with that professional/family member about future adoption referrals.

Another parent, recounting that the community referrals she accessed were not suggested by her local health care provider, said:

We kept telling this [concerns] to the doctor, we kept worrying, we kept saying 'he is small. There are some problems now and we want to do everything to help.' And he kept saying, 'give it time, give it time.' We said 'no, he had too tough of a start and we don't want to do that . . . I'm never going back' [to that doctor].

After accessing a referral to a specialist on her own, one mother said: "When we saw a specialist, we went back and told him [the doctor] everything he said and . . . that was our last appointment with him. We changed doctors after that because we didn't feel that he [the doctor] was his [the child's] advocate or he [the doctor] was really looking at

him [the child].” Finally, one parent recounted that she had accessed a community resource based on the advice she received on the Internet rather than her usual physician. She summarized her feelings saying, “I feel if I hadn’t gone and done that we would still be floundering . . .”

Unexpected Findings

Comments made by study participants also revealed some unexpected findings.

These included:

1. The referral photograph/video was important to parents and impacted on their bonding to that child even when there were medical concerns.
2. Adoptive parents demonstrated persistence and creativity in advocating for their child.
3. Information provided by other parents was as important, if not more so, than information provided by health care providers.
4. Adopting parents viewed the need to accept the “unknowns” in the adoption process much as birth parents do in pregnancy, explaining that birthing and adopting both require a “leap of faith.”

Photographs often accompany the medical report of a referral child. Health care specialists have used these pictures to identify dysmorphic features or to assess physical concerns. What was of surprise in this study was the influence the photograph had on the attachment parents formed to the referral child. For everyone in this study who commented on receipt of a photograph, seeing it cemented the parents’ decision to adopt that specific child despite health record concerns. Although similar findings have been

documented (Johnson & Hostetter, 1996), these have been primarily anecdotal. No specific study focused on this aspect of attachment and it did not seem to be a recurrent theme in other studies of international adoptees and their adopting parents.

One parent who visited the child in the orphanage with intentions of getting an updated video tape for international adoption health experts to view stated:

When we went there, we got this picture of this totally sick child that could not move, that had . . . something wrong with his brain . . . but he was this bright-eyed little boy and he was a life, so basically we were taking him We were supposed to take a video of him and bring it back to the doctors for them to assess to see if we were going to adopt him. Well, so much for that. We're taking the video with me going "Hello! Baby is coming with us."

A mother, who asked for her health care provider's assessment of her child from his referral medical record said: "We just didn't know, because there is the picture, there is the medical Even if you don't like it, it's already your child." Describing his child in a photograph, one father said, "They held him up on the foster mother's lap and like you said, it's yours immediately." Parents later advised prospective adopters not to look at the referral child's photograph before making a decision whether or not to adopt. It was their opinion that the parent would have already begun to "bond" with the referral child, making the decision against adopting him/her based on review of the medical record and advice of experts thereafter difficult, if not impossible.

Although the literature indicates adoptive parents are committed to being parents, the perseverance and creativity parents demonstrated in this study was unexpected. Many parents admitted ignoring the advice of their local health care providers when they did not agree with them and accessing specialists and other resources on their own. One parent said, "A doctor is not helping, what's wrong. I started just going with it, like

‘what do I need to do?’” Another said: “I felt that he had something and then I had to investigate. So, when my pediatrician here told me to ‘relax and don’t worry,’ I didn’t pay attention to him . . . I went and talked to the orthopedic guy here.” Another parent said, “We did a number of things on our own . . . we just didn’t even talk to him [the doctor] about it. We just went ahead [and got a specialist referral].”

As Smith and Sherwen (1983) indicated in their study on the attachment of adoptive mothers and their children, there are similarities in the times prior to, during, and after birth and adoption deliveries. An additional finding in this study was that adoptive parents likened feelings of uncertainty about their prospective child as being like birth parents who do not know every aspect of their child before it is born. “It’s kind of what happens when you get pregnant. It’s the same thing, you don’t know what’s going to pop out at the end of nine months. You just have to have faith.”

Another parent said, “We just decided this was going to be As soon as we decided ‘yes,’ then the whole package was, whatever, it doesn’t matter.” Still, another parent said: “I think for us it made us realize that we don’t have all the answers and we just have to let go, that obviously there are a lot of unknowns when you adopt, and yes, there are a lot of unknowns if you birth the child. But there is a moment that you just have to let go and say ‘yes’ and go for it.”

Physicians (as well as adoption agencies) who had specific information about a country or orphanage or foster care setting were seen as valuable by parents who accessed them. What was a surprise, however, was that parents viewed advice from other parents as just as important, if not more so, than that received from physicians. Agency-coordinated mentor families and get-togethers with other adoptive parents as

well as use of the Internet chat rooms and individual meetings with other adoptive parents were frequently cited as most important resources. For one family, contact with a local restaurant owner who could confirm translation of her daughter's medical report was utilized rather than a health care provider.

When asked for advice for prospective adopting parents, another parent explained: "Get out and seek out people who have done it and look for people who had a hard time because that is where you're going to learn the most." Another parent said, "I learned more from running into [local adoption agency] moms in the store . . . you introduce yourself because you have this little kid . . ."

Additional Findings

Some important information was obtained from this study but was not evident from the structure of data collection. This included comments that the visa physical examination required by all new adoptees before leaving their country of origin were not comprehensive or reliable. The physical exams were poor sources of health information for parents, and the experience was viewed as negative.

One parent said: "The physical was nothing. It was a joke; like 10 minutes. He would dress him and then he would start talking to my husband about [sports] . . . I guess, basically, it was like just paperwork." A parent, who was raised in the same country as her adopted child, was not only surprised but disappointed that the physician recommended to her by the American Embassy treated her with disrespect at the visa physical.

He had lived here in this country for a long time. He never looked at my son. I just wanted to kick him. I was speaking to [child's name] in [language of birth

country] and he just looks at me, this doctor, and says: 'You know, you have to start speaking English, that's going to be his country' and etcetera. You know, that is my decision. I'm his mom, not you! "

While in their children's birth countries, relationships with United States Embassies and adopting parents were reported as negative. As one parent explained, she had tried to "get some information at the American Embassy, which was horrible to work with . . . "

Another parent described a situation she witnessed at the American Embassy in Eastern Europe:

There was a little girl, very small, and very malnourished. They [adoptive parents] took her to the embassy . On the way out they [embassy officials] said 'Oh, her head is too small, she is going to be retarded. Get another one.' And we said to them: "Don't listen, don't listen to them, they're crazy. We've heard these stories. They say the most blatantly disrespectful things and they just don't know what they are talking about . . .

These contacts made an impression on parents and may have influenced perceptions, feelings, and attitudes they had about health care for their child. However, there was no place for this information to be presented as a part of the data received in this study, in view of questions asked.

Limitations

Wording questions so that only positive responses would be obtained was a limitation in this study. As a result, tables only indicate positive results and do not reflect the full picture of parental perceptions, attitudes, or feelings about adoption health information or the sources of information parents accessed. The wording of adoption process time periods as "before adoption" and "after adoption" seemed to confuse study participants. Ambiguity about these time frames resulted in all three groups beginning discussions with the period of time when a referral was received, instead of the intended

prereferral time period. As a result, the researcher had to clarify these time periods during participant interactions. It would have been helpful to explain the time periods to study participants at the beginning of focus group interactions as well as to have been consistent in using the labels that were depicted in the data tables.

One other limitation to this study was that the third focus group had a disproportionate number of families who had adopted from Korea (see Child Demographics, Appendix F). Although focus groups were not intended to be representative of all countries from which parents adopted, equal dispersion among the three groups of parents who had adopted from Korea would have maintained consistency. Whether not doing so affected responses among the three groups is unknown. Finally, as an adoptive parent, the possibility for bias in this study may be present.

Summary

This study of parental perceptions, attitudes, and feelings about health information was guided by the “information and support” category of Kohnke’s (1982) concept of advocacy. This model was shown to be a reliable framework for analyzing how parents advocated for themselves and their children. It also emphasized the view of other parents as important advocates in the adoption process.

Despite some limitations to the study, much information was obtained from the focus group interactions. Many of the findings coincided with the literature, however, some new, unexpected findings were revealed. In addition, some characteristics of adopting families were identified which included persistence and creativity in advocating for the health of their child. Although the focus groups are not intended to be

representative of adoptive families, some of the conclusions suggest that further research is warranted to determine if they could be generalized to the greater population of adopting parents.

Implications and Recommendations

Implications

The findings of this study need further research to determine if they are representative of other adopting families' perceptions, attitudes, and feelings about health care information received at various time periods in the adoption process. Some implications that can be made from this study include:

1. Adoption agencies that can expand their services to include more post placement information and support would serve as a continued resource for adopting families.
2. Parents do not always perceive the importance of having health information about a referral child.
3. Health care providers, especially family nurse practitioners, are in a position to provide information and support that assists parents in advocating for the health of internationally-adopted children.
4. Families' reliance on, and appreciation of, adoption agencies that successfully placed children and were knowledgeable about the conditions in the country of origin were the major source of information and support for families at all phases of the adoption process. This underscores the value of adoption agencies in the adoption process and the importance of the information they provide. Parental satisfaction with

their agencies suggests that post placement services such as receiving additional information, access to resources, referrals to community agencies, and being provided with other ways of support would be welcomed by adopting families.

5. Some parents in this study did not think that additional health information would have made a difference to them in their decision to adopt. However, none of the parents expressed unhappiness with the agency that successfully provided them with a child. Additionally, they did not indicate the development of new concerns post placement for which they had been given more information. What is not known is whether parents would have perceived the health information they received differently if the child they adopted had problems for which they felt unprepared. Despite the kinds and amounts of health care information the parents in this study received, there is still a need to inform parents of expected health issues. Informed consent is a fundamental tenet in assisting clients to make decisions about health care for themselves and their families.

6. Health care providers were viewed positively and negatively by adopting parents in this study. Although many parents accessed specialists, including international adoption health experts for specific concerns and initial assessments, there is still a need for continuing health care for these children. However, some parents chose not to return to their former health care provider because they did not feel they were helpful or supportive in their quest to advocate for the health of their children. This emphasizes the need for health care providers to be accessible and supportive, knowledgeable about the issues of international adoption, concerns of adopting parents, and aware of community resources that can assist them.

7. Studies indicate that the role of a primary health care provider is important for comprehensive and continuous health care. When cared for by specialists alone, there is a risk of incomplete immunizations, routine screening tests not being administered, and developmental issues not being addressed (Jenista, 1999b). A primary health care provider can also play an important role by assisting parents to differentiate between conflicting advice from specialists and helping parents develop a perspective of their child's health issues as one part of their life. Thus, even though a health care provider may not be knowledgeable or experienced with issues related to international adoption, s/he can be educated in these areas. Finally, children have other health needs and concerns, in addition to those related to adoption (Jenista, 1999b).

8. Adopting parents, who realize that their child will need to have a health care provider for continued health assessments and care (e.g., acute illness), will be searching not only for a knowledgeable health care provider but also for one who seems to be interested in the family and supportive of their efforts to advocate for their child. These health care providers, then, might find it beneficial to admit their shortcomings in the area of international adoption health issues, using adoptive families as resources. Becoming knowledgeable in these areas in order to provide information and support to adopting parents would be seen as advocating for them.

Recommendations for Further Research

Further research to explore the needs of adopting families for the sources of information and support that has been most helpful during different phases of the adoption process is imperative to meeting the health needs of prospective internationally-

adopted children and their families. These resources could be provided to prospective adopting families. In addition, identification of specific programs, agencies (e.g., government), and other resources could assist families in identifying and accessing them in their community.

A study to assess health care provider knowledge and sources for obtaining information would be helpful for future dissemination of information and determining the need for specific educational content areas. Identification of medical and nursing programs that include the health of international adoptees in their curricula could be evaluated to determine their effectiveness in meeting the needs of internationally-adopted children.

Finally, adopting parents indicated that the pictures they received of the child being referred to them initiated the bonding process for the parents with that child. Some parents even suggested that photographs not be sent or looked at until the medical records were reviewed because turning down the referral would then be more difficult. The photograph personalizes the referral and parents discover they cannot be objective about it. A study to see if this is a universal finding and how it affects the bonding process with the referral child once adopted would be valuable.

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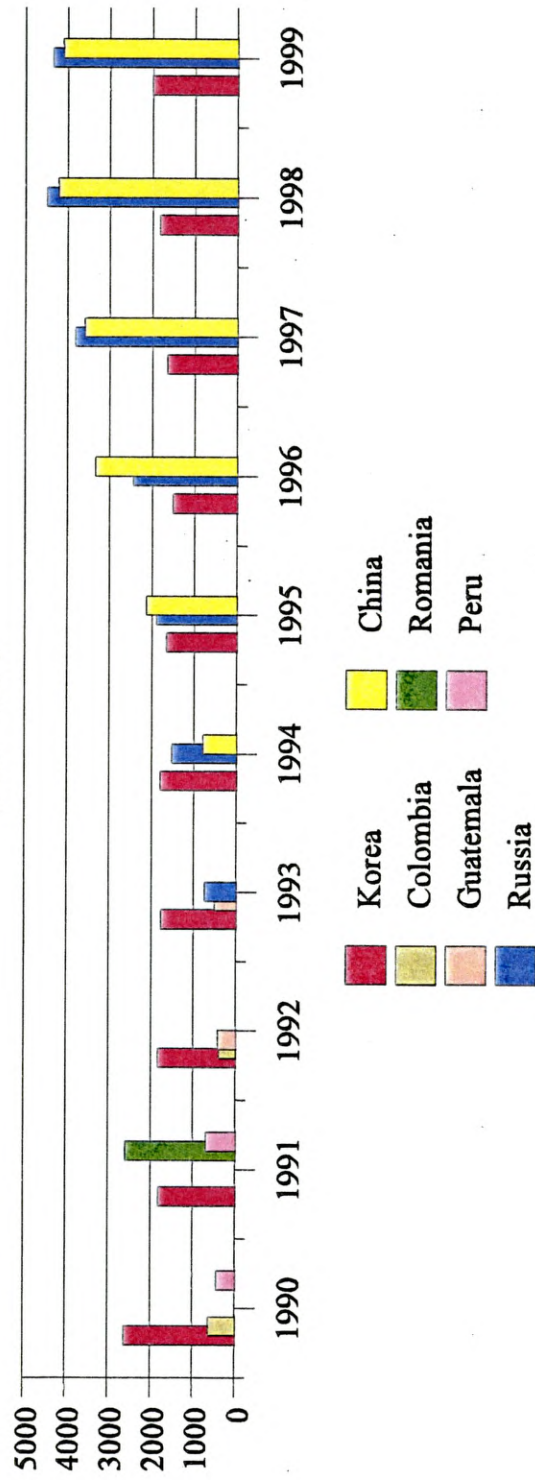
APPENDICES

APPENDIX A

COUNTRIES LEADING IN ADOPTION (1990-1999)

Countries Leading in Adoptions

1990 - 1999



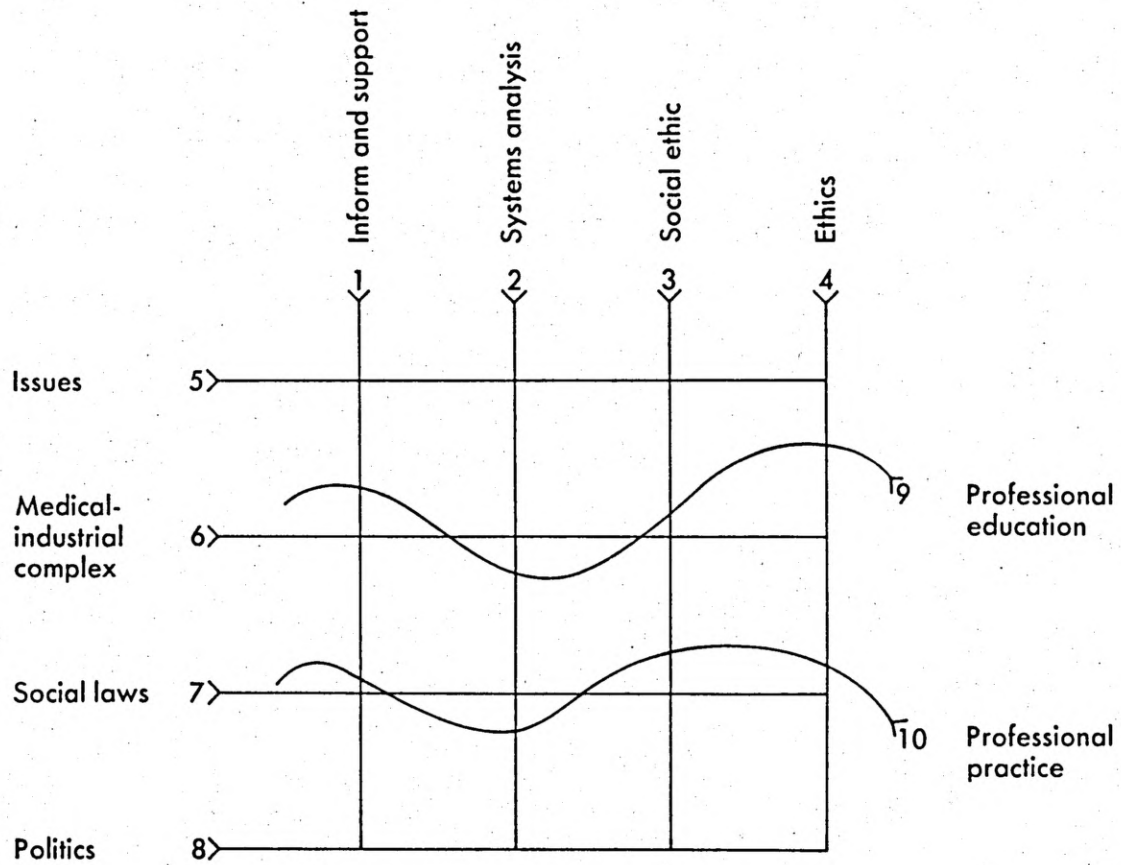
Source of data: U.S. Immigration and Naturalization, 1999

APPENDIX B

KOHNKE'S MODEL OF ADVOCACY

Figure 2

KOHNKE'S MODEL OF ADVOCACY



Source: Kohnke, M. F. (1982). Advocacy risk and reality (p. 4) St. Louis, MO: C. V. Mosby Company.

APPENDIX C

PRE-INCLUSION LETTER

Appendix C: Pre-Inclusion Letter

Date: _____

Dear Parents:

Please consider this letter as a personal invitation to participate in a qualitative research study that focuses on health care information issues as they relate to international adoption. As a graduate student in the College of Nursing/Family Nurse Practitioner Program at Montana State University, Bozeman, Montana, I will be conducting this research as a partial requirement to obtain a Master's Degree in Nursing. Findings for this research may also be used in published articles, books, or presentations.

Participation in the study will involve interactions among a group of 6-8 adoptive parents, gathering in a meeting room on the MSU-Bozeman campus for approximately 2 hours of time. Three separate groups will meet and the dates and times for the meetings will be mutually agreed upon between potential participants and the researcher. If there is an interest to participate by both adoptive parents, each will be placed in separate groups. Participation includes signing this pre-inclusion letter and completing a demographic questionnaire (available at the focus group meeting).

Inclusion in this study and participant contributions (both verbal and written) are completely voluntary. Individuals who wish to participate in this study by signing of this letter agree not to divulge any identifying comments that a participant may make. To this end, participants are not expected, nor are they encouraged, to make any comments that they feel uncomfortable to make.

Participants will be provided opportunities to make comments or ask questions anonymously, in writing, at 30 minute intervals during the 2 hour session. Sessions will be audio taped, however, participant names will not be used on the tape or in the written form of this research. Finally, participants may elect to withdraw from the study at any time without specifying a reason and without penalty for doing so.

The benefits to participating in this study include the opportunity to have a positive effect on dissemination of health care information by providing information about the process based on personal experience. Participation also provides an opportunity to get to know other parents of internationally-adopted children with a common history. Finally, participation encourages discussion of perceptions, attitudes, and feelings about health care information that was provided (or not) during the adoption process from a variety of sources. For those who have had a negative experience with this part of adopting, the focus group format can serve as a form of catharsis.

There is the risk that a participant may breach confidentiality and identify an individual as a source of potentially sensitive information. Likewise, group interactions may evoke emotions that may cause an individual discomfort. Although safeguards are

provided to encourage confidentiality of comments made by focus group participants and to reduce the risk of discomfort that may result from interactions within the group (e.g., signing this letter and having the option to withdraw from the study), some participants may wish to later discuss their feelings with others.

Support for adoptive parents can be obtained locally by contacting:

Hearts and Homes
P. O. Box 8265
Bozeman, MT 59773
(406) 585-8544

Following are Internet support resources for adoptive parents:

St. John's University, Canada
Faces of Adoption

Listser@maelstrom.stjohns.edu
<http://www.adopt.org>

If it is your choice to participate in one of the focus groups, please sign below to indicate that you have read and agree with the provisions of this letter and mail it to me in the enclosed, stamped, self-addressed envelope. Finally, participants are recruited by "word-of-mouth". Therefore, if you know of someone who has adopted internationally within the past 10 years who may be interested in this study, please feel free to give them a copy of this letter or to notify me at the following address about them.

Thank you in advance for your consideration and potential participation.

Respectfully,

Marie S. Mitchell, RN, BSN, CPNP
MSU Graduate Student Researcher
Montana State University
College of Nursing-Sherrick Hall
Bozeman, MT 59717
(406) 585-9234

Therese Sullivan, RN, Ph.D.
Project Advisor
(406) 994-2650

Signature of Participant: _____ Date: _____

APPENDIX D

DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

Note: All "Parent Information" questions refer to "at the time of adoption" except #1 (Current Marital Status) and #3 (Current Age)

Date: _____

Parent Information

1. Marital status: _____
2. Marital status at time of adoption: _____
3. Age: _____
4. Age(s) when child(ren) were adopted: _____
5. Race: _____
7. Ethnic/cultural group (if born outside United States): _____
8. Religion: _____
9. Annual family income: Please check:
 - ___ 0-\$10,000
 - ___ \$10,000-\$19,999
 - ___ \$20,000-\$29,999
 - ___ \$30,000-\$39,999
 - ___ \$40,000-\$49,999
 - ___ \$50,000-\$74,999
 - ___ over \$75,000
10. Government or other subsidies: _____

Children Information

1. Number of biologic children in your family: _____
2. Number of adopted children in your family: _____
3. Age(s) of adopted child(ren) at the time of their adoption: _____
4. Country from which your child was adopted: _____
5. Setting from which your child was adopted: (check one)
 - ___ Orphanage ___ Special institution (specify: _____)
 - ___ Private home ___ Foster care system
 - ___ Other: (specify: _____)

APPENDIX E

QUESTIONS TO GUIDE AND STIMULATE INTERACTIONS

Questions to Guide and Stimulate Interactions

To achieve the aims of the focus groups to obtain information, open-ended questions will be used to lead discussions. These questions include:

- What kinds of health information did you receive before, during, and after adopting?
- In what ways were you supported by your health care provider in your efforts to obtain more information, access resources, or obtain referrals and other ways to advocate for your child's health needs?
- What other sources did you find helpful in supporting the above efforts?
- Which resources/information were most helpful and why?
- If you were going to adopt again or give advice to prospective adopting parents, what information would you insist they access before doing so?
- What other advice would you offer?

APPENDIX F

CHILD DEMOGRAPHICS

Table 15: Child Demographics

Category	Group 1	Group 2	Group 3
Number of families with biological children (47%)	2 with 1 child 4 with 0 children	1 with 2 children 2 with 1 child 3 with 0 children	1 with 3 children 2 with 1 child 2 with 0 children
Number of families with adopted children (100%)	2 with 2 children 4 with 1 child	3 with 2 children 3 with 1 child	1 with 3 children 2 with 2 children 2 with 1 child
Age of child(ren) when adopted	5 months median 6 months mean	8 months median 10 months mean	5 months median 6 months mean
Country where child was adopted*			
China (2) (6.9%)	1	1	0
Columbia (1) (3.4%)	1	0	0
Georgia (1) (3.4%)	1	0	0
Korea (17) (58.6%)	5	5	7
Madagascar (1) (3.4%)	0	1	0
Paraguay (2) (6.9%)	0	0	2
Romania (1) (3.4%)	1	0	0
Russia (4) (13.8%)	1	3	0
Settings of adoptions			
Foster care (19) (65.5%)	5	5	9
Orphanage (8) (27.6%)	4	4	
Private (2) (6.9%)	1	1	

* Some families have adopted more than one child and from more than one country.

APPENDIX G

PARENT DEMOGRAPHICS

Table 16: Parent Demographics

Category	Group 1	Group 2	Group 3
Parent marital status at time of adoption (100%)	All were married	All were married	All were married
Current parent marital status (100%)	Married	Married	Married
Age of parent at time of adoption	37 median 38 mean	41 median 40 mean	35.5 median 34 mean
Current age of parent	40 median 40 mean	45.5 median 45 mean	43 median 44 mean
Race	Caucasian - 5 Latino - 1	Caucasian - 6	Caucasian - 5
Ethnic group if born outside the US		Russian - 1	
Religion	Christian - 6	Christian - 5 None - 1	Christian - 3 None - 2
Income at time of adoption			
\$10,000-\$19,999 (1) (5.5%)	0	1	0
\$20,000-\$29,999 (1) (5.5%)	0	0	1
\$30,000-\$39,999 (1) (5.5%)	0	0	1
\$40,000-\$49,999 (4) (22.2%)	2	1	1
\$50,000-\$74,999 (5) (27.8%)	3*	2	0
> \$75,000 (5) (27.8%)	2*	2	1
Not provided (1) (5.5%)			1
Received nonspecific adoption subsidy	0	2	0

* Responded twice