



Complementary and alternative medicine use in children with chronic health conditions  
by Laurie Bernhardt Glover

A professional project submitted in partial fulfillment of the requirements for the degree of Master Of  
Nursing

Montana State University

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Abstract:

The use of complementary and alternative medical care (CAM) by American adults is increasing. The purpose of this project was to explore the use of CAM by parents for their children with chronic health conditions. Few studies have focused on this area. Insight into the factors which lead parents to use CAM for their children may assist Advanced Practice Nurses (APNs) as they plan care for their clients.

To achieve this purpose, a descriptive design was used for this project, in which the parents of 10 children with chronic health conditions were interviewed. The conceptual framework of the Rogers Diffusion Model provided a guide to identify and characterize factors leading to adoption or rejection of CAM by these families.

CAM utilization among parents for their own health care reflected national rates. Even though only one parent had used CAM providers with her child in the past year, the majority had considered using or had used CAM providers in the past for their children who had chronic health conditions. Most parents (80%) currently used self-directed health practices with their children. Factors which attracted parents to CAM and self-directed practices included convenience, cost, observing positive effects in others, fear of side effects of traditional medical treatments, and compatibility with their spiritual or cultural beliefs.

Parents in the sample were satisfied with their childrens' traditional primary care providers and valued their expertise. However, of particular interest was the unanimous report from parents that their childrens' traditional providers had not asked about the use of CAM.

The study demonstrates the need for primary care providers, including APNs, to a) assess for the use of CAM and self-directed practices in order to provide safe, comprehensive care to families; b) know how to obtain current, evidence-based information on CAM; and c) utilize a variety of channels to provide comprehensive health care information to families of children with chronic health conditions.

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This professional paper has been read by each member of the professional project committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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## ABSTRACT

The use of complementary and alternative medical care (CAM) by American adults is increasing. The purpose of this project was to explore the use of CAM by parents for their children with chronic health conditions. Few studies have focused on this area. Insight into the factors which lead parents to use CAM for their children may assist Advanced Practice Nurses (APNs) as they plan care for their clients.

To achieve this purpose, a descriptive design was used for this project, in which the parents of 10 children with chronic health conditions were interviewed. The conceptual framework of the Rogers Diffusion Model provided a guide to identify and characterize factors leading to adoption or rejection of CAM by these families.

CAM utilization among parents for their own health care reflected national rates. Even though only one parent had used CAM providers with her child in the past year, the majority had considered using or had used CAM providers in the past for their children who had chronic health conditions. Most parents (80%) currently used self-directed health practices with their children. Factors which attracted parents to CAM and self-directed practices included convenience, cost, observing positive effects in others, fear of side effects of traditional medical treatments, and compatibility with their spiritual or cultural beliefs.

Parents in the sample were satisfied with their childrens' traditional primary care providers and valued their expertise. However, of particular interest was the unanimous report from parents that their childrens' traditional providers had not asked about the use of CAM.

The study demonstrates the need for primary care providers, including APNs, to a) assess for the use of CAM and self-directed practices in order to provide safe, comprehensive care to families; b) know how to obtain current, evidence-based information on CAM; and c) utilize a variety of channels to provide comprehensive health care information to families of children with chronic health conditions.

## CHAPTER 1

## INTRODUCTION

American families are faced with a wide array of options as they make health care choices for their members. Increasingly, people are deciding to incorporate non-traditional forms of self-care and providers into their health regimens. In a frequently cited national study published in 1998, 42% of American adults used some kind of complementary and alternative medical care (CAM). This was an increase from 33% in 1990 (Eisenberg et al., 1998).

There is a lack of substantial information in the literature about the use of CAM in the pediatric population. In the limited number of studies that have been conducted, the use of CAM seems to be less common in children than in adults. However, Kemper, Cassileth, and Ferris (1999) found in their literature review that rates of use in children with some types of chronic health conditions appear to be as high as 60-70%.

The Family Nurse Practitioner (FNP) provides health care to people across the life span in a holistic manner. When the FNP provides care to the pediatric client, that child's family is involved as an integral component of the FNP-client relationship. The parents of children with chronic health conditions generally make decisions related to the health care their child uses. It is essential that the FNP is aware of the various modalities of health care used by the client as well as the factors which influence the family's decisions for care.

## Definitions

### Complementary and Alternative Medicine

This project used the definition for CAM from the National Center for Complementary and Alternative Medicine (NCCAM). “CAM” covers a broad range of healing philosophies, approaches, and therapies that mainstream Western medicine does not commonly use (NCCAM, 2002). A few of the many CAM practices include the use of acupuncture, herbs, homeopathy, therapeutic massage, and traditional oriental medicine. Therapies may be used alone, as an alternative to conventional therapies, or in addition to mainstream therapies.

### Pediatric Population

Children who have completed the infancy stage (one year) to the age of 18 were defined as being in the pediatric population for the purposes of this project.

### Chronic Health Conditions

Children who have chronic health conditions have conditions that will not be cured by simple surgical procedures or short courses of medical therapy (Miller, 1992). Asthma and Attention Deficit Hyperactivity Disorder (ADHD) are two examples of chronic health conditions prevalent in children.

### Background and Significance

A major task families undertake in ensuring their unit survival and continuity is to provide for basic needs, including health care for their members. Families provide preventive care as well as the majority of sick care for their members. Families also have the primary responsibility for initiating and coordinating services from health care providers (Edelman, 2002).

Coordination of childrens' health care falls upon the parent or guardian. A number of factors are likely influential in the decisions parents make regarding health care utilization, including the use of CAM, for their children. The parent may weigh input from varied sources such as mass media, family, peers, health care providers, and personal values. Other factors such as perceived health of their children, cost, perceived safety, access, and even fear may be variables in decisions.

The nurse wears many hats when providing health care to families. As an advocate for the family client, the nurse assists the family to obtain needed services and tries to make the health care system more responsive to the client's needs. The nurse is a care manager to prevent duplication of services. The nurse is a researcher, seeking answers to inquiries about variables that affect a client's health (Edelman, 2002). The nurse looks at the whole client, the family, and their multi-factorial health and illness status.

In addition to broad nursing roles, the FNP assesses and manages both medical and nursing problems. The FNP emphasizes health promotion, disease prevention, and

the management of acute and chronic diseases. This includes prescription of pharmacological treatments and non-pharmacological therapies, and monitoring of client response to treatments. FNPs practice in a variety of settings and provide care for individuals, families, and communities (American Academy of Nurse Practitioners, 2002).

In order to be an effective partner in the management of the client's chronic health conditions, the FNP must be aware of CAM use and the reasons for CAM use by clients. The reasons adults use CAM are many and varied. They range from disenchantment with mainstream medicine (Dokken & Sydnor-Greenberg, 2000) to treating existing health conditions, preventing illness, and maintaining health (Eisenberg et al., 1998).

Although there are a limited number of studies available that explore the use of CAM with children, the above factors and more are proposed by the literature as influential when the issue of parents using CAM with their children is explored. One study found three major characteristics differentiating pediatric CAM users from nonusers: the child's age (children were more likely to use CAM if they were older than 1 year), parental use of alternative medicine, and higher maternal education level (Spiegelblatt, Laine-Ammara, Pless, & Guyver, 1994).

Insight into the factors which lead parents to use CAM for their children will assist FNPs as they plan care for their pediatric clients. In light of the significant utilization rate in the adult population, the FNP cannot be ignorant of a corresponding potential use of CAM by members of the pediatric client's family.

The FNP provides care to pediatric clients with chronic health conditions. The literature demonstrates that people with chronic health conditions are more likely to use CAM than the general population (Eisenberg et al., 1998; Kemper et al., 1999; Friedman, Slayton, & Allen, 1997). FNPs provide holistic care, health promotion, anticipatory guidance, education, and advocacy. It is essential that FNPs know the factors relating to CAM utilization by their clients as part of their comprehensive assessment and evaluation of the client's health systems.

### Conceptual Framework

#### The Rogers Diffusion Model

While CAMs are not a new world phenomenon, the use of CAM in the general American population is increasing. This increase in use supposes an "innovation" process, in which more and more people, possibly more parents of children with chronic health conditions, choose to use CAM as an option of medical treatment.

Everett Rogers (1995) described the process of diffusion as that "by which an innovation, or new idea, is communicated through certain channels over time among the members of a social system" (p.35). For purposes of this project, CAM is viewed as an innovation, or practices and ideas perceived as new by the unit of adoption. The units of adoption are the parents of children with chronic health conditions, since they are the ones generally making health decisions for their children.

Some innovations spread more quickly than others. Rogers (1995) described characteristics that influence an innovation's rate of adoption as being 1) relative advantage, 2) compatibility, 3) complexity, 4) trialability, and 5) observability.

The degree of relative advantage is "the degree to which an innovation is perceived as better than the idea it supercedes" (Rogers, 1995, p. 15). The degree of relative advantage may be measured in economic, convenience, and satisfaction terms. Whether an individual perceives the innovation to be advantageous is considered more important than objective measures. This project included assessment of perceived benefits in these areas of substituting or adding CAM to traditional health care practices.

"Compatibility is the degree to which an innovation is perceived as being consistent with the existing values, past experiences, and needs of potential adopters" (Rogers, 1995, p. 15). Parental and family lifestyle and belief factors were explored in relation to CAM use with their children, as well as perceived needs.

Complexity is the degree to which a new idea is considered to be easily understood and adopted. New ideas that are simple to understand are adopted more rapidly than those that require the adopter to develop new skills and understanding. Trialability is the degree to which an innovation may be sampled on a limited basis. New ideas that can be experimented with easily will generally be adopted more rapidly than those that cannot. Parents' feelings of competence, safety, and/or uncertainty could be factors that influence decisions for CAM use.

Observability is the degree to which potential adopters of innovations are able to see results. If they perceive and see favorable results, they are more likely to adopt the

new practice. Parents could theoretically see results of CAM use in their own family members, in the press, or through information provided by their health care providers.

Rogers also described the processes or channels by which new ideas are communicated. He said that mass media channels are more effective in creating knowledge of innovations, while interpersonal channels are more effective in influencing the decision to adopt or reject a new idea. This project examined the types of channels which first introduced parents to CAM such as internet or mass media sources. Just as essential was the gathering of data about interpersonal channels such as health care providers or friends who influence parents in adopting or rejecting CAM practice.

In categorizing adopters based on the degree of innovativeness, or degree to which an individual is relatively earlier than others in adopting new ideas, Rogers lists some characteristics of early innovators. These are the control of substantial financial resources, the ability to understand and apply complex technical knowledge, and frequent interaction with peers or the presence of interpersonal networks. This project objectified these factors when looking at parent factors such as economic status, education level, and amount of interaction with other parents of children with chronic health conditions.

Finally, in Rogers' model, change agents are those individuals who attempt to influence peoples' innovation decisions in ways deemed desirable by the change agent. These change agents may include sales people of CAM products, CAM providers, friends, and neighbors of the family. Primary care providers, including FNPs, who work with families of children with chronic health conditions can be influential in supporting or dissuading parents in the use of CAM with their children. In order to do either, they

need to be aware of the degree of use. An individual seeks information at various stages in the innovation-decision process in order to decrease uncertainty about an innovation's consequences. "The innovation-decision process is the process through which an individual passes from first knowledge of an innovation to forming an attitude toward the innovation, to a decision to adopt or reject, to implementation and use of the new idea, and to confirmation of this decision" (Rogers, 1995, p. 20). The primary care provider is in a position to assess knowledge and provide accurate information to their clients in all of these stages of innovation.

#### Purpose

The purpose of this project was to explore the use of complementary and alternative medical care by parents for their children with chronic health conditions. To achieve this purpose, parents of ten children with chronic health conditions were interviewed. Data from the interviews were analyzed to explore factors that influence parents' decisions to adopt or reject CAM use for their children.

## CHAPTER 2

## REVIEW OF LITERATURE

A summary of the literature relating to CAM utilization in adults and children, including those with chronic health conditions, is reviewed in this chapter. In addition, literature relating to special considerations of families of children with chronic health conditions is explored. Finally, literature on CAM utilization applied to the Rogers Diffusion Model is reviewed.

Complementary and Alternative Medicine UtilizationAdults

Many CAMs have been used for years and are an integral part of particular cultures in other parts of the world. This use is reflected in the US among immigrant populations. What is considered different or alternative for many Americans may be mainstream or the norm for people in other cultures (Dokken & Sydnor-Greenberg, 2000). Eisenberg et al. (1998), in the largest national survey completed in the US, found that 42% of adults use CAM, either alone or in conjunction with traditional medicine. This rate was an increase from 33.8% in 1990 (Eisenberg et al., 1993). The therapies increasing the most according to Eisenberg et al. (1998) included herbal medicine, massage, megavitamins, folk remedies, energy healing, and homeopathy.

In both the 1990 and 1997 Eisenberg et al. surveys, alternative therapies were used most frequently for chronic conditions, including back problems, anxiety, and

depression. Use of CAM was more common among women than men, (48.9% compared to 37.8%), and use was more common among those in the West than elsewhere in the US (Eisenberg et al., 1998). Eisenberg et al.(1998) proposed that the geographical differences could be related to ethnic differences in populations, access, or other factors.

Ernst and Cassileth (1998) reviewed a total of 26 studies of the rate of CAM use by adults with cancer. They found a range in use rates from 7-64% in the studies, with an average prevalence of 31.4%. Ernst and Cassileth (1998) attributed the large degree of variability in use rates to “different understandings of ‘complementary/alternative medicine’ on the part of both investigators and patients” (p. 777).

#### General Pediatric Population

Unlike the adult population, no national studies have evaluated the population and characteristics of children who use CAM (Kemper et al., 1999). In their literature review, Braun, Halcon, and Bearinger (2000) found little CAM utilization or efficacy research based on the pediatric sub-population of adolescents. Dokken and Sydnor-Greenberg (2000) reported that little is known about the impact of CAMs on common childhood conditions or prevention.

Houston and Valentine (1998) reported that CAMs have been accepted and used in perinatal nursing and midwifery practice for decades. Examples include the use of breathing as an alternative for pain relief in labor and birth, the use of massage and comforting touch, relaxation, and the use of a focal point.

In England, complementary therapies are being increasingly used by nurses, midwives, and health visitors as an adjunct or alternative to mainstream treatments. Homeopathy is the most common reason parents give for refusing to have their children immunized in the United Kingdom. Reasons for this were beliefs that immunizations disturb the immune system, natural disease is important to boost immunity, and homeopathic remedies are sometimes used instead of conventional medicine (Thompson, 1999).

In an often cited study involving surveys of 1911 parents consulting a general outpatient clinic of a university hospital in Quebec, Canada, 11% of the children had previously seen one or more alternative medicine providers. Chiropractic, homeopathy, naturopathy, and acupuncture accounted for 84% of CAM use by children in this study (Spiegelblatt et al., 1994). Another finding of their study was children older than 1 year were more likely to use CAM than infants. Parents were the most influential as to which therapy was chosen for children, and parents who used CAM were more likely to use it with their children. The majority of children using CAM used only one CAM modality (Spiegelblatt et al., 1994).

In a survey of 525 parents in an American urban pediatric emergency room, 12% of parents reported using CAM with their children, with the most common modalities being homeopathic or naturopathic (Pitetti et al., 2001). Breuner, Barry, and Kemper (1998) surveyed 157 homeless teens attending a free clinic and found that 70% used alternative medicine. The CAM therapies that were reported by at least 25% of those teens who did use CAM included vitamins, herbs, special diets, special exercise,

massage, acupuncture and meditation. Another method of ascertaining pediatric CAM usage rates is surveying pediatricians. Sikand and Laken (1998) reported that 84% of 348 pediatricians believed their patients used CAM, but 55% thought less than 10% of their patients did so.

### Children with Chronic Health Conditions

A small number of researchers have explored CAM use with different pediatric chronic health conditions, including ADHD, asthma, cancer, autistic spectrum disorders (ASD), and chronic pain conditions.

Respiratory problems are among the most common problems treated with CAM in children (Pitetti et al., 2001; Spiegelblatt et al., 1994). Angsten (2000) in her review of studies relating to CAM use for children who have asthma, stated that asthma is the most prevalent chronic disease of childhood. A variety of CAMs have been used by parents for their children and/or adolescents for themselves.

Ernst and Cassileth (1998) reviewed 4 studies of pediatric cancer patients from Australia, Finland, and the United States. (2 studies). Their findings suggested, but did not show conclusively, a growth in the use of CAM from 9% in 1977 to 40% in 1997 among children with cancer. Friedman et al. (1997) reported as many as 50% to 70% of children with cancer seek CAM care.

More than 70% of university-affiliated pediatric pain management programs use one or more types of CAM, including biofeedback, relaxation therapy, massage treatment, and therapeutic touch (Family Practice News, 1999). CAM utilization rates were significant (64%) in a group of children with ADHD (Stubberfield & Parry, 1999).

### Families of Children with Chronic Health Conditions

The federal Maternal and Child Health Bureau estimates that 18% of children in the U.S. (12.6 million in 1994) have a chronic physical, behavioral, developmental, or emotional condition which requires special health care. The predominant demographics of children with chronic health conditions are African-American, boys, low income, and single parent homes (Newacheck et al., 1998).

Parents of children with chronic health conditions face multiple uncertainties, financial hardships, and the responsibility of ongoing care (Melynk, Feinstein, Moldenhouer, & Small, 2000). Fears, worries, and the need for feelings of competence in dealing with their child's chronic health conditions, especially for mothers, were common themes of parents of chronically ill children (Kohlen, Beier, & Danzer, 2000).

### Literature on CAM Utilization Applied to The Rogers Diffusion Model

#### Relative Advantage

The literature provides some evidence that CAM use provides some perceived economical and convenience advantages, as well as increased satisfaction. The following is a review of this literature.

Eisenberg et al. (1998) reported that adults who were disenchanted with mainstream medicine were more likely to use CAM. While surveys of patient satisfaction among children visiting CAM practitioners are lacking (Kemper et al., 1999), there were several studies in the literature that explored satisfaction. Eighteen percent of parents of children with chronic health conditions reported they were dissatisfied with

one or more aspects of care received at their usual source of care (Newacheck et al., 1998). In the Spiegelblatt et al. study (1994), one-half of parents said they were very satisfied with the results of CAM use in their children. Pediatric patients with chronic, severe pain found acupuncture treatment pleasant and helpful (Kemper et al., 2000). Eighty-seven percent of homeless teens reported CAM helped “some” or “a lot” (Breuner et al., 1998).

Dokken and Sydnor-Greenberg (2000), in their exploration of CAM use in children, proposed that parents may look to CAM practitioners to provide a different kind of relationship for themselves and their children. They reported that visits by children to homeopaths and naturopaths are more frequent and substantially longer than visits to primary care physicians.

The population of homeless teens studied by Breuner et al. (1998) found mainstream care often to be fragmented, inaccessible, or not relevant to their needs. They used CAM because they perceived it to be “natural”. The authors of this study speculated that adolescents from rural areas without access to CAM providers would have the lowest utilization rates. Because alternative nutritional therapies are available in stores without a prescription, this may also be a relative convenience advantage as well as appeal to an adolescent’s desire for independence (Angsten, 2000).

A consideration of all medications is their potential side effects, another fear parents of children with chronic health conditions experience. Chan, Gardiner, and Kemper (2000) stated that parents of children with ADHD have serious concerns about giving their child a psychoactive substance with undesirable side effects for an

unspecified but probably long period of time, even though evidence clearly indicates that stimulant medications are beneficial for this condition. Many herbal and dietary supplements are marketed to reduce the side effects of standard treatments. The use of compelling case reports used in marketing can be very influential. Parents may have the view, right or wrong, that natural is better (Dokken & Sydnor-Greenberg, 2000). Fear of side effects of conventional remedies was cited by 21% of parents as a factor influencing their choice of CAM for their children (Spiegelblatt et al., 1994).

There was a paucity of information in the literature about any perceived economical advantages of CAM use by parents. Eisenberg et al. (1998) reported that expenditures for alternative medicine professional services were conservatively estimated at \$21.2 billion in 1997, with at least \$12.2 billion paid out-of-pocket. Adults of higher economic strata are more likely to use CAM, and the majority of people visiting CAM providers pay all costs out-of-pocket. Comparative figures for CAM use in the pediatric population were not available. The range of costs and insurance coverage or non-coverage for different CAM modalities is likely wide. As one example, behaviorally based interventions for ASD can range from \$20,000 to \$70,000 a year (Hyman & Levy, 2000).

The literature describes financial strains that families of children with chronic conditions experience. In addition, an estimated 11% of children with existing special health care needs were uninsured and 6% were without a source of health care (Newacheck et al., 1998).

## Compatibility

The ways in which the new idea of CAM use was compatible with the values, experiences, and needs of the adopter parents and children was explored in the literature. In the following section this literature is summarized.

Parents who use CAM themselves are more likely to use it with their children, and children who use CAM are more likely to have parents who use CAM (Spiegelblatt et al., 1994; Pitetti et al., 2001). Many parents have become dissatisfied with a passive role in health care (Dokken & Sydnor-Greenberg, 2000), and wished to take an active role in treating their child's condition (Hyman & Levy, 2000).

Parents bring their beliefs about spirituality and religion into their care giving practices. They may use world views to make sense of, and find meaning in, their children's experiences of illness. Believing conventional medical care only addresses limited aspects of the whole person, they may turn to CAM for supplemental or alternative care for their children (Barnes, Plotnikoff, Fox, & Pendleton, 2000).

The use of CAM may be a match with the lifestyle of the family. For some families, CAM therapies may be an integral part of their cultural heritage. In their literature review, Braun et al. (2000) reported higher utilization among Caucasians, Hispanics, and Native Americans, and lower overall utilization among African Americans.

Astin (1998) found that there was increased CAM use by adults who wanted more control over their health. For parents, CAM approaches represent an attempt to gain a sense of control over their child's chronic illness and to improve quality of life (American Academy of Pediatrics [AAP], 2001). The third ranking reason parents gave as

influential in their choice to use CAM with their children was persistent medical problems which, due to their chronic nature, were perceived not to have improved by traditional medical treatment (Spiegelblatt et al., 1994).

CAM use may be compatible with a parental need identified in the literature. Parents need to have a sense of control or helpfulness in caring for their children with chronic health conditions. Kemper et al. (2000) illustrated this intense need in the following quotation. The mother of a child whose symptoms had not been helped by acupuncture said, "I'm very grateful for the acupuncture. It had great value for me, let me feel like I was doing something, like I was a good mom" (p. 944).

CAMS offered hope and options for families desperate for assistance when their children had life-threatening cancer (Kemper, 1999). In diseases that may not be fatal, but rarely have complete resolution of symptoms such as ASD, CAMs offered other options for parents (Hyman & Levy, 2000).

### Complexity and Trialability

The degree to which a new practice is easy to adopt or be tried on a limited basis was explored as it related to families' likelihood of using CAM. Rogers (1995) identified the ability to understand and apply complex technical knowledge as being a characteristic of earlier innovators.

Eisenberg et al. (1998) found that CAM use was higher in those with some college education than in those without college education. Children with higher maternal education levels were also more likely to use CAM (Spiegelblatt et al., 1994). Different factors related to higher education levels such as increased exposure to information and

greater ability to understand different modalities could be involved. There was no association between grade level and prevalence of CAM use in homeless adolescents (Breuner et al., 1998).

Related to a different thread in the theme of complexity is the observation of the AAP (2001) that many parents become frustrated with the bewildering technology and complexity of biomedical therapies. In contrast, CAMs may seem relatively simple and straightforward to these parents, even though scientific data may be lacking.

Certain CAM therapies are more readily available to the public, such as multivitamins and dietary supplements, thus increasing their ease of trialability (Angsten, 2000). Chan et al. (2000) reported that of the nonprescription therapies for ADHD, dietary regimens were the most commonly used.

### Observability

The degree to which others can see the results of an innovation, in this case CAMS, was explored in the literature review. According to Roger's Diffusion Model, when adopters or parents can view results of an innovation, it is surmised they will more readily adopt the new idea.

Astin (1998) reported that perceived benefits of alternative treatments were substantive determinants of use in adults. Perceived benefits were defined as relief of symptoms and improvement in condition compared to that while using traditional treatments.

These perceived benefits may be perceived by one's self or observed or reported by others known to the family. Parents may be inspired by positive claims of products for

treating cancer or boosting the immune system, even though many CAM remedies have not been adequately tested in children (Kemper, 1999). The course of maturation in children with neurologic impairments varies, which leads to unwarranted claims that improvements in their conditions were the result of a specific form of treatment (AAP, 1999).

### Channels

Using the conceptual framework of the diffusion of innovations, channels are the processes by which new ideas are communicated (Rogers, 1995). Literature on potential channels that promote CAM use is reviewed in the following section.

The media, Internet, condition-specific publications, and peer contacts provide opportunities for families to learn about resources, including CAM (AAP, 2001). Health care providers also were channels for communication in the literature. In the Kemper et al. (2000) report of CAM use in children with chronic pain, one man said his pediatricians had referred him for acupuncture treatment for his daughter to treat her chronic pain. He further indicated that he would not have considered acupuncture if the pediatricians had not made this referral.

One half of surveyed pediatricians in one study said they would refer for CAM therapies (Sikand & Laken, 1998). In a second study, sixty-five percent of surveyed Nurse Practitioners in Connecticut, including those who provided care to clients across the lifespan, said they have referred for or recommended CAM. The specific therapies these NPs indicated they were most knowledgeable of included massage, meditation, imagery, chiropractic, and prayer and spiritual healing (Hayes & Alexander, 2000).

Parents were the most influential as to which therapy was chosen for their children using CAM , and word-of-mouth was found to be the most common factor influencing choice of CAMs in parents of children (Spiegelblatt et al., 1994). Peer referrals likewise were found to be essential with homeless teens. Referrals to CAM most often came from friends of homeless teens (Breuner et al., 1998). Angsten (2000) speculated that adolescents may be particularly drawn to using alternative therapies due to the credence they give anecdotal claims from peers.

### Change Agents

Change agents are those people potentially influential in supporting or dissuading parents in the use of CAM with their children. These agents can include CAM providers, peers of the parents, and traditional health care providers. This project focused on the application of the change agent concept to primary care providers such as pediatricians and Advanced Practice Nurses.

The AAP (2001) stated that parental questioning of their child's treatment reflects a normal process of adapting to the chronicity of the condition, and wanting the best outcome for their child. This adjustment need of parents conjoins well with the primary care provider role of anticipatory guidance and health promotion.

However, not all people using CAM discuss that decision with their health care providers. Almost all (96%) of survey respondents who consulted an alternative practitioner for a principal condition also saw a medical doctor during the prior 12 months. Only 38.5% of the alternative therapies were discussed with the medical doctor

(Eisenberg et al., 1998). In Pitetti et al.'s (2001) report, 39 of 59 caretakers (70.9%) reported informing their child's physician of CAM use.

Perhaps some parents are not talking about CAM use because they are not asked about it by their providers. More than half (54%) the pediatricians talked about CAM with their family clients, but 84.7% of these physicians said the discussion was initiated generally by the patient's family (Sikand & Laken, 1998). Forty-nine percent of Nurse Practitioners in Connecticut said they asked about their clients' use of CAM therapies (Hayes & Alexander, 2000).

There were a variety of reasons cited in the literature for primary care providers to discuss CAM use with the families of children with chronic health conditions. Many health professionals and parents alike are concerned about the safety of CAM therapies (Dokken & Sydnor-Greenberg, 2000). Safety issues include concern about potential allergy responses, dangerous side effects, and interference with conventional treatment effects (Hyman & Levy, 2000)

Families searching for treatment options may not discriminate between anecdotes or personal experience and scientific evidence. It was deemed important for providers, or change agents, to find out what families are reading and hearing and steer them toward the most authoritative sources (Chan et al., 2000). When providers do not ask and are not aware of which treatments a child is receiving, improvements might mistakenly be attributed to other treatments that are potentially more costly or unsafe (Kemper et al., 2000).

Cattell (1999), in an analysis of the NP role in CAM, asserted that the assessment of CAM use is integral to the NP's cultural assessment and symptom analysis. Kemper (1999), a leading authority on CAM use in children with chronic health conditions, maintained that pediatricians should routinely ask families about CAMs they have used or are considering. Pediatric primary care providers need to ask about perceived benefits, costs, and side effects of CAM; and make available evidence-based information to assist parents in their decision making.

### Summary

Complementary and alternative medical therapies are increasing in use to the point of becoming a significant portion of the American public's health care time and resource expenditures. CAM use in the pediatric population, especially in children with chronic health conditions, appears to be significant.

Many of the perceived relative advantages to adopting CAM were common to both adults and children in the studies reviewed. This is not surprising, as parents make health care decisions for their children, and generally choose practices that are compatible with their experiences and values.

While adults using CAM often want to have more control over their health, parents of children with chronic health conditions may have compounded feelings of wanting to be a positive force in their child's recovery or enhanced quality of life. Because of this, they may be especially vulnerable to the information provided them through the various channels described in the literature review.

Finally, many primary care providers are referring for CAM and some are asking their clients about CAM use. There are compelling reasons for the provider to be cognizant of common CAM therapies and the scientific studies available. They need to open the field of discussion with families and share information which will assist families in making decisions that are safe and beneficial for their children.

## CHAPTER 3

## METHODOLOGY

The following chapter summarizes the methods used to address the purpose of this project including the data collection procedures and project design. This section also includes a description of the population sample, survey instrument, and human subjects protection process. Finally, the method of data analysis is discussed.

Project Design and Data CollectionProject Design

The purpose of this project was to explore the use of complementary and alternative medical therapies by parents for their children with chronic health conditions. Because certain characteristics of a single sample of parents were explored, a descriptive design was used. This type of design involves identification of a phenomenon of interest and the variables within the phenomenon, and description of the variables. The researcher then interprets the theoretical meaning of the findings and provides implications for practice and future research (Burns & Grove, 2001). The descriptive design of this project included a questionnaire guided by concepts from the conceptual framework and literature review.

Sample Selection. Parents of 10 children with chronic health conditions were selected through a convenience sampling procedure. Convenience sampling does not control for biases, so the researcher needs to be aware of and describe biases in the

sample. A convenience sample was chosen for this study because it is useful in areas that are not well explored, rather than well-explored areas that need confirmatory studies. The sampling procedure in this study could also be said to be quota sampling, as the researcher took steps to ensure the inclusion of subject types that may have been underrepresented in a convenience sample (Burns & Grove, 2001). The researcher ensured a sample with a variety of chronic health conditions, ages, and both genders. The researcher also purposely included Native Americans, as Native Americans constitute the largest minority group in Montana (US Census, 2000).

The researcher approached parents by telephone call to recruit their involvement in the study. Potential participants were known to the researcher through personal and professional channels. None of the subjects were under the care or health supervision of the researcher, currently or within the past year. Parents were included if their children had a chronic health condition as defined in the project and their children were between the age of 1-18 years. Parents were included if they were the primary care givers/health decision makers for their children, as perceived by the parent.

Instrument and Data Collection Procedures. A survey questionnaire instrument was used for face-to-face interviews. The investigator adapted the instrument for use in this study from the data collection tool used in the National Center for Complementary and Alternative Medicine, National Institutes of Health-funded study, (1R15AT09501) "Complementary Therapies in Rural Areas"; Principal Investigator, Jean Shreffler-Grant; Co-Investigators, Clarann Weinert, Elizabeth Nichols, and Betty Ide. Because their tool was designed for an elderly population sample, and was also designed for telephone

interviews, this investigator adopted questions applicable to the pediatric population and their parents for face to face interviews. Questions were also added to explore concepts unique to this project. The tool was reviewed by two parents of children between the ages of 1-18 to ascertain clarity before it was administered to participants. (See Appendix A, Interview questionnaire).

Before the interviews took place, the researcher contacted each potential participant by telephone. At this time the purpose of the project was explained, as well as the participants' freedom of choice in participating, the anticipated length of time commitment (one hour) for the participant, and the confidentiality precautions. Appointments were arranged for the actual interviews, and care was taken to make these at times and places convenient and private for the participants.

The interviews took place in the families' homes (9) or in the parent's workplace (1), depending on the participants' preferences. An informed consent form was reviewed with each subject before the interview to ensure their understanding of purpose, confidentiality, benefits, and risks. Each participant signed the consent. (See Appendix B, Consent Form). There were negligible anticipated risks involved in participating in the study. Confidentiality was ensured by only the interviewer having access to identifying information. Participants were assured that their responses would only be shared without identifying information. Participants were assured that the quality of their future health care would not be affected by their decision to participate in this project.

### Human Subjects Approval

The investigator planned the study with the consideration for the rights of human subjects. The project proposal was submitted to the Montana State University-Bozeman College of Nursing Human Subjects Review Committee. The proposal was submitted in May, 2002, and approval to proceed with the project was received on May 13, 2002.

The benefits for participating in this study included the opportunity for each participant to contribute to the body of nursing knowledge about health care practices of families of children with chronic health conditions. This knowledge may have benefits to individual providers and their clients when the providers incorporate CAM assessment and knowledge into their practice. It may also have further reaching effects as being part of an increasing number of studies on CAM, which combined, may influence national research and practice policies that benefits families. In addition, each participant had the opportunity to discuss their beliefs and experiences about health care.

The only possible risks involved to participants in this study included inconvenience and anxiety about sharing personal information. However, the investigator stressed freedom of participation in the interview, in whole or in part. Interviews were also scheduled at the participant's convenience. Confidentiality was addressed when subjects were assured the investigator would remove identifiers before making data available for publication, and would not share the data in identifiable form with anyone.

### Data Analysis

Quantitative data from the interview instruments were cleaned, checked, coded, and entered into SPSS for analysis. Descriptive statistics were used to describe the data and address the project's purpose. Variables were examined that specifically were associated with the conceptual framework. Because of the small sample size, the researcher did not examine relationships between variables, but instead concentrated on describing the data as it applied to the sample and the conceptual framework.

Several questions on the interview tool were open-ended, and thus yielded qualitative information. These data were organized into themes using the conceptual framework as a guide, through content analysis. Content analysis (Burns & Grove, 2001) is a qualitative analysis technique used to classify text into themes, and describe the intensity of occurrence of those themes in the text.

## CHAPTER 4

## PROJECT OUTCOME

Over a time frame of two months, parents of ten children with chronic health conditions were interviewed by the project investigator. After contacting families by telephone and obtaining consent, interviews took place in family homes in all but one instance. One interview took place at the parent's workplace by her choice. Interviews varied from 40-90 minutes in length. The data were coded and all identifying information removed. The quantitative data were then entered into the SPSS data analysis software program. The qualitative data were organized by categorizing and identifying themes using the conceptual framework as a guide.

Demographics

All parents interviewed had a child with a chronic health condition, and the parent interviewed was one of the major caregivers for that child. The parents ranged in age from 25 to 46 years with a mean of 39. The children ranged in age from 1-14, with a mean of 9 years of age. Nine of the parents interviewed were female; one was male. Six of the children were male; four were female.

Eight (80%) of the ten parents interviewed reported themselves to be Caucasian, while two (20%) of the parents reported themselves to be Native American or American Indian. Most of the parents interviewed (80%, N=8) were married; one parent was divorced and one was single, never married. The years of education completed by the

parents who were interviewed ranged from high school education to more than college, with a mean of 14 years. All of the parents interviewed had completed high school, and three parents had 15 or more completed years of education. Most of the parents (70%, N=7) had lived in Montana for 10 or more years.

All who presently used or had used CAM in the past reported they paid for it out of their own pockets; their insurance and health plans did not cover it. The annual family income before taxes, employment category of interviewed parents, and health insurance status for the child with chronic health condition are shown below in Tables 1, 2, and 3.

Table 1. Income Categories of Families (N = 10).

<u>Income Categories</u>	<u>n</u>	<u>%</u>
Less than \$8000/yr.	2	20%
\$20,000-30,000/yr.	2	20%
\$30,000-40,000/yr.	3	30%
\$40,000 or more/yr.	3	30%

Table 2. Employment Categories of Interviewed Parents (N= 10).

<u>Employment Categories</u>	<u>n</u>	<u>%</u>
Full-time for pay	7	70%
Part-time for pay	2	20%
Full-time homemaker	1	10%

Table 3. Health Insurance Categories of Child with Chronic Health Condition (N = 10).

<u>Health Insurance Categories</u>	<u>n</u>	<u>%</u>
Private insurance only	1	10%
Medicaid only	2	20%
Both Medicaid and private insurance	4	40%
Military or other government programs	3	30%

The parents were asked to list their child's significant health problem or problems. Only one parent listed one condition. One parent listed eight significant health problems. The average number of health problems listed per child was three. The significant health problems as listed by the parents included the following: chronic lung problems (2), asthma (3), cerebral palsy (4), hearing loss (5), vision loss (2), autism (2), obesity (1), ADHD (2), seizures (3), cognitive delays (2), susceptibility to infection (4), behavioral problems (1), cystic fibrosis (1), and chronic constipation (1).

Even though most of the children had more than one chronic health condition as listed by their parents, when asked to rate their child's general health, the mean rating was 3.8, on a 5 point scale with "5" being excellent and "1" being poor. This could reflect the unique perspective of parents of children with chronic conditions; one parent qualified his answer with "he's a lot better than he has been." The response to the question regarding how much their child's physical health limited the child's daily activities ranged from "no limitation" to "a lot of limitation." Most parents (70%, N=7) said their child's physical health resulted in "some limitation" or "a lot of limitation" in the child's activities, such as attending school and playing.

Nine of the parents interviewed stated their child's primary health care provider was a pediatrician. One parent said her child saw pediatricians and medical specialists, as well as CAM providers, but she did not consider any of the providers to be the child's "primary provider." This parent considered herself and her partner to be the coordinators between the various providers her child saw.

All of the families (90%) except one lived within 5 miles round-trip of their child's primary care provider and emergency care facility. One family lived within 10 miles round-trip. All of the children had seen their pediatricians within the past year. Seven had seen their pediatricians six or less times, and three had seen their pediatricians seven or more times. One child had seen his pediatrician 15 times in the past year. The majority of parents interviewed (90%, N=9) stated it was either "easy" or "fairly easy" to see their child's pediatricians.

#### CAM Utilization

Four (40%) of the ten parents interviewed had used CAM therapies, provided by a practitioner or provider, for their own health care in the past year. The CAM providers utilized by these parents included chiropractors, massage therapists, and naturopaths. Seven (70%) of the ten parents had used self-directed practices for themselves in the past year. These practices included yoga, vitamins, exercise, herbs, over-the-counter medications, prayer, meditation, sage, and sweetgrass.

Only one parent (10%) reported she had used CAM providers with her child in the past year. This family had utilized a massage therapist, naturopath, and craniosacral therapist with their child who had chronic health conditions. Two other parents (20%) reported having used CAM providers with their children, but not in the past year. The providers they had utilized included naturopaths, acupuncturists, chiropractors, spiritual healers, and craniosacral therapists. Four more parents said they have considered CAM providers for their children, but have not actually tried them. Their reasons are explored

later in the project report. Thus, seven of ten parents (70%) have used, were presently using, or have considered using CAM providers for their children who had chronic health conditions.

Eight of the ten parents (80%) interviewed used self-directed complementary health practices with their children in the past year. Participants were able to identify what CAM practices they defined as "self-directed complementary health practices" within the parameters provided in the survey questions (See Appendix A, Survey Questionnaire, p. 5). These practices included oil massages used for agitation; a "salt sock", described as a home remedy to draw out pain and fever; omega 3 and flax oils because they "are supposed to be good for the respiratory system"; horse-riding therapy; Mountain Dew soda to improve concentration; over-the-counter medications for minor illness treatment (2); vitamins for general health (2); daily honey for general health; dietary supplements for weight maintenance; exercise and stretching (2); yoga; prayer (2); and music.

#### Findings on CAM Utilization Applied to The Rogers Diffusion Model

##### Relative Advantage

Seven of the ten parents (70%) interviewed rated the care from their child's health care provider (pediatrician) as excellent. One parent rated the care as very good, and the other two parents rated care from their child's pediatrician as fair. Another parent elaborated on the "excellent" ranking of their pediatrician's care with these words, "our doctor even does house calls...we're close friends with [our child's] doctor." Yet another

parent stated, "It's wonderful to have a pediatrician who looks at the whole picture." One child with a chronic respiratory condition was seen by a multi-disciplinary team every three months. The parent declared, "I think it's great...they can keep tabs on how she's doing and nip problems in the bud. I don't know if she'd be doing this well if we didn't have clinics every three months."

Several parents discussed the hardship of establishing trust with a new provider after they or their physician had moved. One parent summarized this by saying, "it's tough...our doctor is leaving...we're going to have a hard time trusting other doctors." The parents who were not as satisfied with the care of their child's health care providers provided the following comments: "[Our child] has seen many specialists. The higher you go, the less bedside manner they have." "When you go to the pediatrician, they are focused on the acute problem. [Our child's CAM provider] was more holistic."

The same parent who described CAM provider care as "more holistic" talked about her child's CAM providers coming to their home to provide therapy. "The setting is so important...[providers] miss that environmental component [when they don't come to the home]." She said her child was "not himself" in the clinic setting of a development specialist they had seen. The parent felt this affected the evaluation and plan of care.

The one parent who had used CAM providers with her child in the past year rated the care as "excellent" and "extremely helpful." This family had spent approximately \$770.00 from their own pocket on CAM care for their child in the last year. They traveled over 100 miles to see one CAM provider, and their other CAM providers were located within 5 miles of their home. Another parent said she had considered

chiropractic care for her child, but did not follow through when she found their health insurance would not cover the care.

Of the eight parents who reported using self-directed complementary health practices with their children in the last year, three parents rated the practices as “extremely helpful,” two parents rated the practices as “somewhat helpful,” and three parents rated the practices as “moderately helpful.” One-half (4) of these parents reported spending no money or an insignificant amount on the self-directed practices; the other four parents said they spent between five and sixty dollars per month.

Concerns for their child’s safety influenced parents’ decisions to use and not use CAM providers and self-directed practices. An example of the mixed feelings of a parent who has considered CAM therapy for her child follows: “Drugs for hyperactivity bounced him off the walls....seeing as I’m not getting anywhere with doctors, I’m willing to try anything....doctors don’t want to diagnose; all they want to do is pump (the child) full of medication.” This parent also stated, “I worry about the effects of mixing herbs with medications....I’m not going to subject him to snake venom....I’m not some holy roller...I would try anything on myself first.” Another parent stated, “I’ll try everything to help him [child] breathe better....steroids are puffing him up.”

### Compatibility

The parent who used CAM providers for her child in the past year also used CAM providers for her own care. Of the eight parents who reported using self-directed health practices with their children, five also used self-directed practices for their own care.

The parent using CAM provider care with her child used it for symptom treatment of the child's chronic health condition. The eight parents who used self-directed practices with their children used them for both general health promotion (5) and illness/symptom treatment (5). Some parents indicated use for both purposes. Several parents described years of taking an active role in their child's health. One parent summarized years of hopeful seeking, "We tried everything...naturopath, acupuncturist, magnets,....we even went to Boston."

The questionnaire also surveyed parents about their spiritual and cultural beliefs and values. The investigator desired to determine if parents' beliefs affected their choices for health care for their children. Seven of the ten parents indicated that spiritual beliefs and values were either "very important" or "extremely important" in their lives. However, six of the ten parents did not feel their spiritual beliefs and values affected their choices for health care or health providers for their child. One parent said her spirituality was associated with Native American beliefs, and she would like to learn more about Native American herbs, "but right now I trust her doctors." Another parent said her initial choice for a provider for her child was not affected by their spiritual beliefs but "I was glad to hear he [physician] was a Christian later on."

Of the 40% who stated their spirituality did guide their health care choices, several said praying, meditating, and "looking to their inner selves" were processes that helped them feel comfortable with their choices. One parent said her spiritual beliefs were instrumental in deciding not to discontinue life support when her child was a

critically ill infant. This parent further explained, "My child's life is what it's supposed to be...it's not a mistake."

Seven parents identified with a culture or more than one culture. A culture was defined in the questionnaire as "a group one identifies with based on shared values, ethnic or racial heritage, or religion." The variety of cultures the parents identified with included Caucasian (4); Native American (3); African-American (1); Deaf culture (1); Catholic (1); Hinduism (1); Buddhism (1); Shamanism (1); World culture (1); and contemporary artist culture (1). Of the 10 parents interviewed, only two felt their cultural or ethnic values and beliefs affected their choices for health care or health providers for their child.

One parent who did state her religious and cultural beliefs affected her health care choices said, "I have to feel good within myself about health care choices....only way I can be secure is through prayer." Two parents stated their choices for healthcare providers and CAM providers were limited by the choices available in Montana. One parent speculated that her cultural values may cause her to be more open-minded and curious, more ready to "try alternative processes rather than going down the surgical or medical path which aren't always very successful." One parent who identified with both ethnic and religious cultures felt his choices for his child's care providers were not affected by cultural beliefs. "All we want is workers [hard-working care providers] and honesty," was his statement.

### Complexity and Trialability

As previously reported, all the parents interviewed had at least a high school education. The parent who reported she had used CAM providers with her child in the last year had 19 years of education. Some parents described conducting their own research into CAM therapies, such as a parent who was reading a book about biofeedback and another parent who related reading "Omega 3 and flax oils are supposed to be good for the respiratory system" in a popular press health magazine. The self-directed health practices eight of the parents used with their children were of the type that are available to the general public, for example honey and Mountain Dew. One parent described acquiring primrose oil and flaxseed oil from a health food store which she tried to treat her child's attention and learning problems.

### Observability

As discussed previously, all parents who used either CAM providers or self-directed care with their children rated the results of the care as helpful to some degree. Parents reported learning about the CAM providers or self-directed practices from family members, friends and traditional health care providers.

One parent stated that an extended family member had the same health condition as her child. "They tried herbal and holistic treatments which didn't work for them...biofeedback did help him, though....I'm considering biofeedback [for child]." Another parent said she was influenced to continue craniosacral therapy with her child because "when we first started he didn't want to be touched...at the end he would fall asleep in her [CAM provider's] arms."

### Channels

Six (60%) of the ten parents reported having regular contact with other parents of children with chronic health conditions, although only three parents had one hour per week or more contact. The most common type of contact with other parents was through individual personal friendships (6), followed by internet friendships (3), and newsletter (3).

The parent who used CAM providers with her child in the past year learned of the CAM providers by her own research and reading, as well as recommendations from a physician and other parents. Parents who used self-directed practices with their children learned of the practices from health care providers (4); their own parents (3); and their own reading and internet research (2). None of the parents reported being approached by a CAM provider or sales person initially.

### Change Agents

Parents who used CAM therapies with their child in the past year were asked if they shared the fact that their child sees a CAM provider with their child's regular health care provider. The one parent who responded positively to recent CAM provider use with her child said she "always have disclosed everything that's happening [with her child's health status]. We don't think of a division line between alternative and medical care. We actually have forced [the regular provider] to include herbs along with prescription medications [on the child's medical record]."

All parents were asked if their child's primary or regular health care provider had ever asked them if they use complementary health care with their child. All parents

responded “no”, their providers had not asked about CAM use. One parent said, “He [provider] just asks how he’s doing...quick physical...doesn’t inquire much of anything.” Three of the eight parents who used self-directed practices with their children had not reported the practices to their child’s physician. The practices not reported included vitamins, herbs, and dietary supplements.

### Summary, Discussion, Limitations and Implications

This study included a convenience sample of parents, purposely designed to have a small sample conducive to personal interviews. The children with chronic health conditions were of both sexes, a range of ages, and had a variety of health problems. They and their parents had coped with these conditions for a number of years, thus were able to provide meaningful insights into their choices of health care for their children. Lack of access did not seem to be a significant factor for most of the parents, though several did say their overall choices for all types of providers were somewhat limited in Montana.

CAM utilization among parents (40%, N=4) for their own health care was consistent with national rates of 42% for adults (Eisenberg et al., 1998). Although only one parent (10%) had used CAM providers with her child in the last year, six others (60%) had considered CAM use or used it in the past. The majority of parents (80%, N=8) were using self-directed health practices with their children. Even though there is not much data in the literature about childrens’ use of CAM, the rate of self-directed

practices use is somewhat higher than that found in the literature, which showed rates varying from 11-70% by children.

Parents in this study primarily used pediatricians for their child's regular health care. Overall, they were satisfied with the care pediatricians provided to their children. They had developed trusting relationships with their pediatricians, and dreaded having to build new provider/family relationships when circumstances required it. Even though they were satisfied with the care of their primary providers, some parents listed factors which attracted them to CAM and self-directed practices, such as convenience, cost, observing positive effects in others, fear of side effects of traditional treatments, and compatibility with their spiritual or cultural beliefs. The feelings and sentiments expressed by the parents led the investigator to believe that each parent desired to obtain the best and most effective care possible for their child with the greatest associated safety.

Parents were influenced by a variety of channels in their choices for health care for their children. While most had some regular contact with other parents of children with chronic health conditions, they were often influenced to use alternative health care choices by their own family members and traditional health care providers as well. These channels illustrate the need for including as many caregivers as possible in the assessment and plan of care for children with chronic health conditions. Health information can be incorporated into newsletters for parents, as this is one channel used by parents to keep abreast on health information and maintain contact with other parents. Continuing education must also be targeted toward health care professionals, including

physical therapists, nurses, and primary care providers. Parents obtain advice and referrals from their child's providers.

Of particular interest is the unanimous report of the interviewed parents that their childrens' primary health care providers had not asked about the use of CAM. Parents valued the opinions of their childrens' providers and talked of the trust they placed in them. If the parents' perceptions that their primary providers are not assessing for CAM use is accurate, providers are missing an important opportunity to provide education and support to parents as they care for their childrens' holistic health needs. Providers, including pediatricians and advanced practice nurses, can provide evidence-based information to parents about the potential benefits, harms and/or complementary actions of CAM and self-directed health practices. Parents and children can benefit from the respect and care providers demonstrate by taking the time to assess thoroughly in order to provide safe, comprehensive care to families.

Because of the size of the sample, the findings cannot be generalized to all populations of parents of children with chronic health conditions. Even though this was a small convenience sample of parents, the sample included families from a variety of income levels, ages, and ethnic backgrounds.

There are broad implications for future research from this project. These parents used pediatricians as primary providers for their children. The needs of these families are complex, as the study families related in their interviews. Research is needed on practice models of advanced practice nurses who work in collaboration with pediatricians and

who provide comprehensive care to children with chronic health conditions. Are APNs, specifically FNPs, currently capitalizing on their family assessment and health education skills to provide care to families? Is the provider office, the family home, or a combination of both the most efficient and effective setting for care? Once families are provided with comprehensive assessments and education regarding all their health care choices, do they make decisions which are safe and advantageous for their children, while still reflecting their values and beliefs? What is the CAM knowledge base of primary providers for children with chronic health conditions? Do providers know where they can obtain current, evidence-based information on CAM? All of these questions are worthy of nursing research and have implications for nursing practice in providing comprehensive care for families.

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APPENDICES

APPENDIX A  
INTERVIEW GUIDE

INTERVIEW GUIDE  
Laurie Glover, RN  
Professional Project

1. Are you the major caregiver or one of the primary caregivers for your child?
2. In what month and year were you born?
3. In what month and year was your child born?
4. How long have you and your child lived in Montana?
5. How long have you lived in this community?

**General Health and Social Contacts**

6. What are your child's significant health problems?
7. On a scale of "1" to "5", with "1" being POOR and "5" being EXCELLENT, how is your child's health in general?
8. In the past month, how much has your child's physical health limited his/her daily activities, such as attending school, playing, participating in extracurricular activities, ranging from NO LIMITATION to A LOT OF LIMITATION?  
1 NO LIMITATION    2 SOME LIMITATION    3 LOT OF LIMITATION
9. What contact(s) do you have with other parents of children with chronic health conditions?
  - 1     Support group
  - 2     Newsletter
  - 3     Educational groups
  - 4     Computer (Internet) groups
  - 5     Individual personal friendships
  - 6     Computer (Internet) friendships with other parents
  - 7     Other
10. What is the total amount of time you have contact with other parents of children with chronic health conditions?     Specify approximate time per day, week, mo.

**Health Care**

11. Does your child have a health care provider who takes care of most of their health care needs?
12. Is the health care provider your child sees most frequently a:
  - a. Physician
  - b. Nurse practitioner
  - c. Physician's assistant
  - d. Clinic staff or provider group in same practice
  - e. Other: \_\_\_\_\_
13. In the past year, how many times has your child been to see his/her provider (from above)? Specify number of visits
14. How far does your child travel one way to see their health care provider?  
Specify number of miles
15. Using a scale of "1" to "5", with "1" being EXTREMELY DIFFICULT and "5" being EASY, how easy is it for your child to go see his/her health care provider (from Q12)? (i.e., transportation, mobility, getting an appointment, etc.)  
1 EXTREMELY DIFFICULT    2 VERY DIFFICULT    3 DIFFICULT  
4 FAIRLY EASY                      5 EASY
16. Using a scale of "1" to "5", with "1" being POOR and "5" being EXCELLENT, how would you rate the care from your child's health care provider (from Q12)?  
1 POOR    2 FAIR    3 GOOD    4 VERY GOOD    5 EXCELLENT
17. Now in terms of emergencies, such as a serious cut or a bad fall, how many miles would your child need to go for emergency medical care? Specify miles
18. Where would your child go for emergency care?
  - a. Hospital
  - b. Provider's office
  - c. Clinic
  - d. Other: \_\_\_\_\_

### COMPLEMENTARY AND ALTERNATIVE CARE

There are many options for health care today in addition to doctors, nurse practitioners, and physician assistants. For example, some people see complementary providers such as chiropractors, acupuncturists, herbalists, massage therapists, or spiritual healers.

19. Have YOU seen this type of provider in the past year?
20. If so, what kinds of complementary providers have you seen in the past year?
21. For each complementary therapy provider in order, how did you hear about this (insert from Q20)?
22. Has your child seen a complementary provider in the past year?
23. If no, have you ever considered using a complementary provider for your child? (Ask for specifics) Then, skip to Q31
24. What kinds of complementary providers has your child seen in the past year?
25. For each complementary therapy provider in order, how did you hear about this (insert from Q24)?
26. Would you say your child sees this (insert from Q24) for a particular problem or mostly to promote and maintain their health? (answer for provider most often seen)
  - a. General health promotion
  - b. Illness/symptom treatment (including chronic problem)
  - c. Acute injury
  - d. Other: \_\_\_\_\_
27. If your child is being seen to treat a particular problem, what is the problem?
28. What other health care providers does your child also see for this same health problem?
  - a. Do not see another provider for this problem
  - b. See a primary or specialist care providers
  - c. See another complementary provider  
(Indicate types of providers seen) \_\_\_\_\_
29. Do you share the fact that your child sees (insert from Q24) with your child's primary or regular health care provider?



### Self-directed Practices

People adopt many other practices to enhance their health or treat their symptoms that are not provided through a health care system, things like meditation, vitamin therapy, dietary supplements, etc. We consider these practices to be "self-directed", since no provider is involved in your use of them. Do you understand what I mean by "self-directed" practices? If no, give other examples such as home remedies, yoga, etc.

37. Are there any self-directed practices like I have just described that you use for your health?
38. What self-directed practices do YOU regularly use?
39. How did you find out about using this practice?
40. Are there any self-directed practices like I described that your child uses for his/her health?
41. What self-directed practices does your child regularly use or do you use with your child?
42. How did you find out about using this practice?
43. How frequently does your child use this practice? Specify number times per day, week, month
44. Would you say your child uses (insert from Q41) for a particular problem or mostly to promote and maintain his/her health?
  - a. General health promotion
  - b. Illness/symptom treatment (including chronic problem)
  - c. Acute injury
  - d. Other: \_\_\_\_\_
45. If your child is using (insert from Q41) to treat a particular problem, what is the problem?
46. How much do you think you have spent on this practice in the past month? (Include any materials used, books, cost of vitamins/herbs, etc)

47. Using a scale of "1" to "5", with "1" being NOT HELPFUL AT ALL and "5" being EXTREMELY HELPFUL, how would you rate how much this practice has Helped you with your health or health problem?

- |   |                    |   |                  |
|---|--------------------|---|------------------|
| 1 | NOT HELPFUL        | 2 | SOMEWHAT HELPFUL |
| 3 | MODERATELY HELPFUL | 4 | QUITE HELPFUL    |
| 5 | EXTREMELY HELPFUL  |   |                  |

### **Spiritual Practices**

The next set of questions is about spirituality. We're defining spirituality as a sense of connection to a higher being, nature, others, or the inner self. For some people, spirituality is associated with the health care choices they make.

48. How important are spiritual beliefs and values in your life?

- |   |                      |   |                    |
|---|----------------------|---|--------------------|
| 1 | NOT IMPORTANT        | 2 | SOMEWHAT IMPORTANT |
| 3 | MODERATELY IMPORTANT | 4 | VERY IMPORTANT     |
| 5 | EXTREMELY IMPORTANT  |   |                    |

49. Have your spiritual beliefs and values affected your choices for health care or health providers for your child? (e.g., choice of medical care provider, complementary provider, and/or self-care practices) If so, how?

### **Ethnic/Cultural Practices**

The next set of questions is about ethnicity or cultural practices. We're defining a person's culture as a group he or she identifies with based on shared values, ethnic or racial heritage, or religion.

50. Do you and/or your child identify with a specific culture? (Specify if YES)

51. Have your cultural or ethnic values and beliefs affected your choices for health care or health providers for your child? (e.g., choice of medical care provider, complementary provider, and/or self-care practices)

**Demographics**

52. What is your present marital status?
- a. Married
  - b. Divorced
  - c. Separated
  - d. Widowed
  - e. Never married
  - f. Common law
  - g. Living together
53. What is the total number of years of school you have completed, including grade school, high school, any college, or vo-tech? Specify number years
54. How are you employed?
- a. Full-time for pay
  - b. Part-time for pay
  - c. Full-time homemaker
  - d. Retired or disabled
55. How many people, including yourself, usually live in your house/apartment?
56. What is your racial or ethnic background?
- a. Asian-American
  - b. African-American
  - c. Caucasian/White
  - d. Native American Indian
  - e. Hispanic/Latino
  - f. Other \_\_\_\_\_
57. If your child were hospitalized tomorrow how would the bill be paid?
- a. Self-pay
  - b. Medicare
  - c. Medicaid
  - d. Other government (Veterans, Indian Health, etc.)
  - e. Private insurance
  - f. Other: \_\_\_\_\_

58. If your child went to see his/her primary or regular health care provider how would the bill be paid?
- Self-pay
  - Medicare
  - Medicaid
  - Other government (Veterans, Indian health, etc.)
  - Private insurance
  - Other: \_\_\_\_\_
59. If your child went to see their complementary health care provider how would the bill be paid?
- Self-pay
  - Medicare
  - Medicaid
  - Other government (Veterans, Indian health, etc.)
  - Private Insurance
  - Other: \_\_\_\_\_
60. If your insurance plans or government insurance has paid for these visits, can you tell me which complementary therapy treatments have been covered?
61. Counting all sources of income, including wages, interest, government payments, gifts, etc., what is an estimate of your total family income during the last year, before taxes?
- Less than \$8000
  - \$8000-\$20,000
  - \$20,000-\$30,000
  - \$30,000-\$40,000
  - \$40,000 or more
  - Declined to answer

APPENDIX B  
CONSENT FORM

Subject Consent Form for Participation in Human Research at  
Montana State University

Complementary and Alternative Medicine Use in Children with Chronic Health Conditions  
Laurie Glover, RN, MSU-Bozeman FNP Student  
Great Falls Campus, 406-771-4443  
Jean Shreffler-Grant, Committee Chairperson  
Missoula Campus, 406-243-2540

You are being asked to participate in a study to gather information on health care used by Montana children with chronic health conditions. The reason for this research is to begin to determine how many children with chronic health conditions are using complementary health care options, what influences families to use these types of care, and their satisfaction with health care choices. This may help health care providers better understand how to care for children and their families. You were identified as a possible subject for this research because you are a parent and one of the major care givers of a child with a chronic health condition.

If you agree to participate, you will be asked approximately 60 questions over a total period of about an hour. The study is of no material benefit to you. Precautions will be taken to maintain anonymity in reporting, but there is a risk that participants may be identified.

Your responses to these questions will be kept confidential. The researcher will remove identifiers such as names and cities before combining information into the final report. All questionnaires and consents will be secured in a locked file in the College of Nursing for 5 years.

You may decline to participate at any time, even if you have already begun the interview. There is no cost to you for participating in this study. The researcher covers any costs. You may ask questions of the researcher interviewer at any time. The Chairperson of the College of Nursing Human Subject Review Committee, Dr. Charlene Winters, Missoula Campus, 406-243-4608, can answer additional questions about the rights of human subjects.

AUTHORIZATION: I have read the above and understand the discomforts, inconveniences and risks of this study. I, \_\_\_\_\_ (name of parent or guardian), related to the child as \_\_\_\_\_ (relationship) agree to my participation in this research. I understand I may later refuse participation in this research. I understand I will receive a copy of this consent form for my own records. I also understand I can receive a summary of the research results upon request.

Signed: \_\_\_\_\_  
Investigator: \_\_\_\_\_

Witness: \_\_\_\_\_  
Date: \_\_\_\_\_

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