BABIES AND THE ENVIRONMENT: CONDUCTING FOCUS GROUPS TO DETERMINE PRIORITY PEDIATRIC ENVIRONMENTAL HEALTH ISSUES ON A NORTHWEST AMERICAN INDIAN RESERVATION

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Milissa Renee Grandchamp

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DEDICATION

I want to dedicate this endeavor to my wonderful family who stood by me through this journey. First of all to my husband John thank you for your support and faith in me to do this; there were so many times I wanted to quit and walk away, but your encouragement kept me going. You have been an awesome provider and cheerleader. Thank you for all your prayers and strength to walk with me. To my son Arley, thank you for your thoughtfulness and patience. Thank you for staying focused on your future even when I was too preoccupied to help you. Keep moving forward, striving toward your goals. To my daughter Ashley, you are awesome. You have a bright future ahead of you. Thank you for being patient with me despite a part of my expedition seeping into your senior year. My children you are people of high character and I am very proud of you. I pray God's favor on you in all of your future endeavors. To my parents Harold and Arlene; thank you for planting and nurturing seeds of wisdom to carry me through this journey called life. I am blessed to call you mom and dad. To my sisters Norrie and Pam thank you for believing in me and encouraging me. I have the best sisters ever. Finally, to my pillar I am thankful to my "Gramma Carrie Old Person" who has gone to be the Lord while I was on this path of higher education. You will forever be in my heart; because of you and my walk with creator God, I will always know who I am and where I come from.

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ABSTRACT

American Indian/Alaska Native infant mortality rate is disproportionately higher than the dominant culture. Excess mortality and morbidity for this population may be linked to exposures such as environmental tobacco smoke (ETS), metal contaminants; outdoor air pollution, pesticides, and polychlorinated biphenyls (Karr 2010). Health care providers (HCPs) are positioned to identify, prevent and treat environmental exposures (EE). However, HCPs often lack basic and continuing education on pediatric environmental health (PEH) topics. The purpose of this study was to work with community partners to offer PEH training via a HCP conference on one northwest reservation. A descriptive, qualitative research design utilized focus groups to query HCP about their perceptions of local PEH issues. Moderators were trained via a written protocol to lead focus group discussions using a 12-question instrument. Discussions were audio recorded and transcribed. Content analyses were completed to identify the most frequent themes and question inter-rater reliability was established. The results of this study found that health care providers perceived environmental health (EH) as prevention of both physical toxins and behavioral aspects of population health. Excess infant/child mortality and morbidity were linked to sudden infant death syndrome (SIDS), and a lack of family/community education and resources. Substance abuse (drugs, alcohol, ETS) was recognized as a priority EH issue. Health care providers described their role in PEH as serving as and referring caregivers to resources. A barrier to implementing PEH into practice included the low priority of silent and unseen issues versus conditions with visible acuity. Resources were identified as potential interventions needed to protect the fetus, infant and child from harmful EE. Lack of coordination among agencies creates gaps in policies. Local tribal groups were recognized as entities to advocate for PEH issues. Health care provider identified ways to enhance their knowledge of PEH. In conclusions focus groups are a valuable approach to community-based participatory research. Local HCPs find PEH to be an important topic and are interested in increasing their knowledge. The recommendations are future focus groups on this topic should reorder the tool questions. The findings of this study should be returned to community groups for further action.

INTRODUCTION TO THE STUDY

Introduction

"Although the health status of American Indians (AI) has improved considerably since the creation of the Indian Health Service in 1955, disparities in maternal and infant health, compared to other populations, persist" (Alexander, Wingate, & Boulet, 2007, p. S5). As late as 2003, the mortality of American Indian infants continued disproportionately higher than that of white infants by 24 percent (Alexander, et al., 2007). Guadino (2008) found that AI/AN (Alaska Natives) infant mortality continued to be 1.5-2.0 times greater than that of Whites. AI ranked second in infant mortality, after non Hispanic Blacks. In 1999-2001 the infant mortality rate, under the age of one, for all races in the United States (U.S.) was 6.9 per 1000 live births but for Indian Health Service (IHS), the rate was 8.8 per 1000 live births. The local regional IHS reported 9.8 infant deaths per 1000 live births. The leading causes of death for the Billings Area IHS were sudden infant death syndrome (SIDS), short gestation/low birth weight (LBW), and neonatal hemorrhage. This closely reflects the U.S. for all races which includes rates of congenital anomalies, short gestation/LBW and SIDS (United States Department of Health and Human Service [USDHHS], IHS, 2008). Maternal child health disparities among American Indians have been an ongoing challenge to the health care system. Other researchers have uncovered possible risk factors to explain the higher rates among the population.

> Risk factors associated with poor birth outcomes included: a) delayed or inadequate prenatal care, b) pregnancy induced hypertension, c) diabetes, d) smoking, e) alcohol use, as well as f) marital status, g) maternal age, h) parity and i) maternal education. Overall, socioeconomic disparities also plague AI communities as evidenced by high rates of unemployment, poverty, and low education levels (Alexander et al., 2008, p. S5-6).

In 2007, experts presenting at the Tribal Nations Children's Environmental Health Summit suggested that environmental exposures may also affect the mortality rates of AI/AN infant and child health. During the summit, Karr (2007) identified asthma as the leading chronic disease among children, and that AI/AN children in the state of Washington had higher hospital admission rates due to asthma exacerbation. Keel (2007) identified that methamphetamine use was associated with adverse affects on the social and physical health of children. Vogel (2007), Boulafentis (2007), Master (2007) and Runs Through (2007) expanded on the developmental effects of children related to poor air and water quality, including, adverse pregnancy outcomes, low birth weight, and adverse neurologic, endocrine, and reproductive development; as well as congenital anomalies and chronic respiratory disease (US Environmental Protection Agency [EPA], 2007).

Identification of potential exposures to environmental toxins may be a possible link to reducing infant mortality and morbidity on reservations. Prevention often begins with awareness and discovery of potential hazards. To the best of our knowledge, no reservation-specific studies have been conducted to identify primary environmental hazards that could contribute to excess fetal/infant/child mortality and morbidity.

Background of the Study

The key to determining an infant or child's health risk is the identification of hazardous environmental exposures (Sattler & Davis, 2008). Environmental exposures that frequently place children at increased risk in the U.S. include environmental tobacco smoke, metal contaminants (i.e. lead, mercury), outdoor air pollution (i.e. particulate matter, dust), pesticides on surfaces/soils and food residues, persistent organic pollutants (POPs) (i.e. PCB's and plastics) (Karr, 2010). However, we do not know the specific exposures in local tribal areas that could put AI children at risk for excess morbidity or mortality. Diseases most commonly identified in children linked to environmental exposure include asthma, neurologic developmental disorders, obesity, endocrine disorders and cancer (Hill, 2010). Once again, given this data, it is not known if the local area is similar to national trends.

Health care providers (HCPs) are in a unique position to evaluate and identify potential environmental exposures that place the fetus, infant and child at risk. Therefore, HCP expertise is crucial in order to gain insight into potential exposures and priority issues for children. However, in order to determine risk, the degree of pediatric environmental health understanding and educational needs must be evaluated (Trasande et al. 2006a). Despite research findings indicating that children bear much of the burden of environmental illnesses (Perera et al. 2006), continuing evidence points to the need for improved healthcare provider education to increase the ability to recognize environmental health-related issues (Trasande et al., 2006a; Tradande et al., 2006b, Balbus, Harvey, McCurdy 2006).

Healthcare providers often lack initial primary education on environmental health topics and often lack resources and opportunity to gain expertise through continuing education. One study identified that health care professionals lack the formal training in environmental health necessary to adequately manage and treat diseases related to environmental exposures. (Rogers, McCurdy, Slavin, Grubb, & Roberts, 2009). In two different studies conducted by Trasande et. al (2006a; 2006b) in New York and Wisconsin, health care providers admitted a lack of proficiency in dealing with diseases related to environmental exposures except when dealing with lead. The providers surveyed indicated a need for more formal education to better address environmental health conditions. Areas identified by health care professionals in which they felt they lacked training and proficiency included environmental history taking, and discussing environmental exposures with parents as well as finding diagnoses and treatment resources related to environmental exposures (Trasande et al. 2006a).

In response to this challenge the *Healthy People 2020 Objectives* identify specific goals for increasing the environmental health curriculum content at schools educating medical doctors, doctors of osteopathy, undergraduate nurses, nurse practitioners, and physician assistants. Under the topic area "Educational and Community-Based Programs" the data indicate that in 2008 just 85.7 percent of M.D granting medical schools provided education in environmental health as required courses. Healthy People 2020 have a target of improvement in this area set at 93.4 percent. Furthermore, only 74.3 percent of nurse practitioner schools included content on environmental health in required courses. The target for improvement for the NP profession is 81.7 percent. Registered nurses have a

target of improvement of 100 percent from 94 percent (USDHHS, 2010, ECBP 12.4, 13.4, 14.4, 15.4, 16.4). Health care providers attending medical or nurse practitioner school prior to 2008 likely have had even less environmental health education than recent graduates.

Statement of the Problem

Fetal, infant and child mortality and morbidity is significantly higher in American Indian children compared to the dominant culture. In 1999-2001 the infant mortality rate for IHS was 8.8, exceeding the U.S. rate of 6.9. The local regional IHS service unit, which represents all IHS service units across one northwest state reported an infant mortality rate of 9.8, the fourth highest of all twelve IHS service units across the United States (USDHHS 2008). Exposure to toxins is one preventable cause of illness and death. Although healthcare providers are uniquely positioned to serve as partners to reduce environmental exposures, many lack formal or continuing education in environmental health and often have little or no experience with community-based participatory research approaches to prevention efforts. Trasande et al. (2006a) stated that although pediatricians function in a role to have a reduction impact to exposures to environmental hazards, they lack training to feel competent in this area. Pediatricians agreed that an environmental history would be helpful in their role in helping reduce a child's exposure to environmental hazards. Most participants in the study identified lead exposure and tobacco smoke as the areas where they felt the most equipped with talking to parents. However, they rated their self-efficacy much lower in areas of pesticides, mercury and

mold exposures (Trasande et al., 2006a). Community based participatory research approaches are designed to gain insight into the community so that research will have more intimate meaning to local communities. Developing partners can be challenging due to time and resources. However, local community participation is vital for the best outcomes in such a research approach (Cashman et al 2008).

Purpose

The purpose of this study was first, to work with a community-academic partnership to sponsor an environmental health continuing education event for health care providers working with the tribal and non-tribal local population; second, to utilize a community-based participatory research approach to tap local health care provider expertise and identify potential environmental exposures on one Northwest Indian reservation and the principal county within the reservation; and finally, to gather information on future environmental health education needs of local health care providers.

Research Questions

The research questions for this study are as follows:

1. What are the perceptions of health care providers regarding environmental hazards that could affect fetal, infant and child morbidity/mortality?

2. What are the potential environmental health issues that could impact the fetus infant and child on the reservation-of-interest?

3. What are the health care provider educational needs related to improving competencies in environmental health?

Conceptual/Theoretical Frameworks

There are two models that apply to this study: first, the TERRA (translational environmental research in rural areas) framework proposed by Butterfield and Postma (2009); second, the Community-Based Participatory Research Analytic Model reported by Viswanathan et al. (2004). The TERRA model applies directly to the subject matter of this study (environmental health issues). Although the model targets risk reduction in parents and families, the framework could be adapted to help categorize the pediatric environmental health deficits of health care providers serving families in rural areas. The authors of TERRA identified the need for a foundational framework for "strengthening nursing's rapidly evolving body of science addressing environmental health and environmental justice by emphasizing the areas of risk and risk perception" (Butterfield & Postma, 2009, p. 107).

Secondly, the Community-Based Participatory Research Analytic Framework (CBPR/AF) developed by Viswanathan et al. (2004) represents the inclusive approach to this research project that honors the voice and participation of community members throughout each stage of the process. CBPR values the strengths that each participant has to offer. CBPR is designed to be a collaborative effort among researchers and the community experiencing the phenomena studied. The methods for this framework aims toward combining knowledge and action of the researcher and community in order to promote social change that will result in improved health of communities as well as reduce or dissolve health disparities producing outcomes that will be specific to local community needs and sustaining results (Wallerstein, Duran 2010).

Significance of the Study

The top three causes of infant death in the local regional Indian Service Area include sudden infant death syndrome (SIDS), prematurity and neonatal hemorrhage. The death rate related to sudden infant death syndrome (SIDS) is three times higher for American Indian infants than for white babies within the state of Montana and has been directly linked to exposure to environmental tobacco smoke and other causes (USDHHS 2008). The data identified by the Indian Health Service in regard to health disparities among American Indians and the disproportionately high rates of infant mortality are regionally based and do not provide a local perspective. Given the vast land range and geographical differences, each community on the reservation has plenty of opportunity to have their own environmental risk factors that could impede fetal, infant and child health. Therefore, further research is needed in order to determine information important to a local community. This information is essential when trying to identify issues that could impact a specific area. Recognizing issues in this case, environmental hazards, is important in order to move toward implementing intervention through research, education, and policy.

Madeline Leininger's Theory of Culture Care helps highlight the cultural significance and perspective of the population of interest in this study (American Indians living on one reservation). This theory considers the cultural diversity of groups of the same ethnicity (McFarland 2006). Although compiled as one ethnic group, American Indians and Alaska Natives are made up of culturally diverse groups with their own traditions and languages that not only set them apart from one another but from the nation

as a whole. The Culture Care model allows the researcher to approach the subject matter with sensitivity to the cultural issues that might present throughout the research process. Roubideaux (2002), stated, “We must all resist the temptation to enter Indian communities as ‘experts’ who will control programs and outcomes. A more productive role is to be a resource to the community and to help build local capacity” (p. 1403). CBPR allows the researcher to work with local communities, in this case a Montana Indian reservation, to isolate specific information reflective to the area. By doing so, we will be able to identify issues that impact the morbidity and mortality of the fetus, infant and child. Through the research process, areas of risk could potentially be identified that might also move towards action and change to decrease present health problems and disparities.

Limitations

The data gathered for this research study utilized focus groups. Focus groups have limitations that require consideration. The data gathered from focus groups is dependent not only on the skills of the moderator to promote discussion but the generation of data is highly dependent on the participation of group members. The responses to the focus group questions were impromptu and based on personal and professional experiences. Each focus group was audio recorded and participants did not identify themselves therefore individual clarification of a response was not possible. In addition, participation was voluntary so data collected was limited to individuals invited and willing to contribute their insights. With focus groups there is the potential for one person to want

to dominate the conversation, while others may be more reserved and less contributory. As a result focus groups were created based on years of experience and area of work.

Assumptions

Health care providers are in a position to observe and intervene on environmental health hazard issues. Health care providers with limited background and education in pediatric environmental health but with community expertise are, nevertheless, uniquely positioned to describe potential hazards after receiving an overview of potential issues. Mortality and morbidity can be reduced in AI communities if awareness is raised of potential issues among health care providers.

Health care providers can provide the best insight into their educational needs on pediatric environmental health. Health care providers are at the forefront of identifying potential environmental health risks in the pediatric population. Therefore, they are the best informants for identifying appropriate and needed educational topics. Healthcare providers are also capable of identifying the most useful and accessible methods of delivery on educational topics.

Definition of Terms

To bring understanding to the study and how terms are used this section identifies key terms that are used throughout the study to describe subjects and processes. The definitions will interpret how terminology is used to discuss concepts.

Health care provider: Individual healthcare professionals providing health care to children on the studied Reservation, including medical providers, public health nurses, WIC providers.

Mortality: Death rate; in life insurance, the ratio of actual deaths to expected deaths (Dorland's 2007, p.1200).

Morbidity: The incidence or prevalence of a disease or of all diseases in a population (Dorland's 2007, p.1199).

Pediatric environmental health: "The diagnosis, treatment and prevention of illness due to preconception, prenatal, perinatal and pediatric exposures to environmental hazards; and the creation of healthy environments for children." (Children's Environmental Health Network Training Manuel, 1999, p. 7, http://www.cehn.org/file/Manuel_Full_Version.pdf).

Health disparities: The National Institutes of Health defines health disparities as the "differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions that exist among specific groups in the United States (NIH National Cancer Institute, http://crhd.cancer.gov/about/defined.html 2011)."

Community based participatory research: A research approach designed to bridge the knowledge of the researcher and the community in order to address health and environmental issues and eliminate health disparities. (Viswanathan 2004, p. 1)

Focus group: A group of individuals gathered together to provide their input on a topic, the group is lead by a mediator. Groups consist of 4 to 12 people. The group is lead by a mediator whom asks questions pertaining to the subject at hand in order to

gather rich information that the researcher can use to guide research projects (Polit & Beck 2008, p.394-395).

Organization of Study

This research study is presented in five chapters. Chapter one includes the background of the study, statement of the problem, purpose, significance, theoretical framework, research questions, limitations, assumptions and definition of terms. The literature review will be presented in chapter two and will include infant/child mortality/morbidity and health disparities, health care providers pediatric environmental health competencies, toxins, exposure pathways and pediatric susceptibilities and theoretical frameworks . The third chapter will describe the methodology used for the study, including the research design, selection of participants, instrument used (Appendix A), data collection, and data analysis processes. The findings of the study are presented in chapter four and include demographic information and analysis and results of the data for the three research questions. Chapter five will conclude with a summary of the entire study. Findings and conclusions are also discussed in this chapter along with implications of the findings for theory and practice as well as recommendations for the further research.

CHAPTER 2

REVIEW OF LITERATURE

Introduction

This study utilized a community-based participatory research approach to first, tap local health care provider expertise in order to identify potential environmental exposures on one Montana American Indian reservation and the principal county within the reservation; and second, to gather information on environmental health education needs of local health care providers. American Indian infants have a higher mortality rate than that of dominant culture in the United States. Many of the infant mortality studies evaluate death as a result of disease, illness, or chronic conditions. The literature linking infant/child morbidity and mortality to specific environmental exposures is less prevalent but knowledge of the unique susceptibility of the fetus, infant, and child has grown exponentially in recent years. Tracking environmentally mediated childhood illnesses began in the early 1990's with the observation that exposure to chemicals and poor air/water quality contributed to excess morbidity and mortality in children as well as life-long chronic illness effects (Brent & Weitzman, 2004; Landrigan, Schechter, Lipton, Fahs, & Schwartz, 2002; National Research Council, 1993; Wigle, 2003; Woodruff, et al., 2004). The launch of initiatives such as the Children's Environmental Health Network in 1992 (CEHN, 2011; Etzel, 2010) promoted the need for child-focused national policy, research, public awareness, and pediatric health education for health professionals. However, despite recommendations to include environmental health in

medical and nursing curricula (Etzel, 2003; Institute of Medicine [IOM], 1995), schools have been slow to integrate pediatric environmental health competencies into programs that are burdened with competing content priorities. As a result, many of today's health care providers who graduated 10+ years ago and perhaps even more recently, may have little knowledge of the unique exposure pathways, susceptibilities, or the costs of subsequent illnesses to the fetus, infant, and child. In 2002, the costs of four chronic environmentally-related illnesses, lead poisoning, asthma, childhood cancer, and developmental disabilities, were estimated at 54.9 billion a year (Landrigan et al., 2002). By 2008, the cost of these same illnesses had increased to 76.6 billion per year (Trasande & Liu, 2011).

The primary emphasis of this review of literature focused on first, a brief overview of recent epidemiological studies of American Indian infant mortality; second, the current status of pediatric environmental health education for health care providers; third, relevant pediatric exposures to environmental toxins and topics of concern for health care providers; and finally, the literature related to the theoretical frameworks used for this study.

Search Process

Two search engines were used to discover the pertinent literature. The Cumulative Index to Nursing and Allied Health Literature (CINAHL) is a "multidisciplinary bibliographic database covering nursing, allied health, biomedicine, and consumer health literature" and has been in place since 1981 (CINAHL Resources,

2011, p. 1). The National Library of Medicine PubMed/Medline is “the premier medical abstracts database covering the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and the pre-clinical sciences” and covers journal articles published since 1966 (PubMed Resources, 2011, p. 1). In addition to refined searches, articles were reviewed and serendipitous and linked literature were discovered including classic environmental health articles.

For infant mortality, a combination of search terms were used including “infant mortality” and “American Indian” (68 results); adding date limitations (2006-2011) (14 hits). Adding the word “disparities” resulted in six articles. For literature related to environmental education for health care providers, the CINAHL and PubMed searches using the same search terms “pediatric environmental health” “environmental health” “health care providers” “education” uncovered 25 and 30 articles, respectively, with article overlap seen among the databases. On the topic of pediatric environmental toxins, a broad ranging topic, a sample of literature was collected using the search terms “child” “environmental toxins” “morbidity” and limiting the search to the most current literature (2006-2011). This search strategy reduced the number of articles from an initial result of over 2000 to 78 and finally to 12.

Discussion of Search Results

Infant/Child Mortality/Morbidity and Health Disparities

There is a significant amount of literature pertaining to the topic of infant mortality. Much of the epidemiological research relates to causes of death in order to

bring awareness to the public on the afflictions suffered by infants and children. Infant mortality is often the result of sudden infant death syndrome (SIDS) across cultures (Gaudino, 2008). Low birth weight (LBW), pre-term birth (PTB), and small for gestational age (SGA) are also a leading factors associated with neonatal death (<28 days) and infant mortality (<1 year) (Baldwin et al., 2002; 2008; MacDorman, 2011; Taylor, Alexander, & Hepworth, 2005).

Researchers often agree that infants and children are at increased risk for mortality and morbidity related to the environment (Alexander, Wingate, & Boulet, 2008; Brender et al. 2006; Woodruff, Darrow, & Parker, 2008). Infants have limited or no control of their surroundings and are highly dependent on others to protect them from potential harms in the environment. Fetal, infant, and child health is also highly dependent on very early life development in the womb (Woodruff et al., 2008; Castor et al., 2006). However, the science of cause-effect linkages between specific environmental hazards/toxins and death or disease reported as specific conditions, sudden infant death syndrome (SIDS), low birth weight (LBW), pre-term birth (PTB), and small gestational age (SGA), is still a developing field (Brent & Weitzman, 2004; Landrigan et al., 2002; Woodruff, et al., 2004). A multi-determinants model and longitudinal studies are necessary to answer complex environmental exposure questions.

Related to this need, the National Children's Study is a long-term research project that will "examine the environmental influences on children's health and development. The work studies health outcomes and exposures, (pregnancy-related outcomes, injury, asthma, obesity/diabetes/physical development, and child development and mental

health), complex interactions, genetics, and priority exposures (physical, chemical, psychosocial, and biologic environment). The study is supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), Centers for Disease Control and Prevention (CDC), United States (U.S.) Environmental Protection Agency (EPA), and the National Institute of Environmental Health Sciences (NIEHS) and will recruit up to 100,000 participants with plans to follow the cohort from birth to 21 (National Children's Study, 2011).

Maternal health during the developmental stages of the fetus is a strong determinant of the health and well being of the infant/child (Alexander, Wingate, & Boulet, 2007; Baldwin et al. 2008). Infant exposure to prenatal tobacco smoke and to environmental tobacco smoke (ETS) has been associated with changes in heart rate (MacDoran, 2011; Schuetze & Eiden, 2005). Lower maternal educational achievement, low socioeconomic status, age, marital status, and pre-existing conditions (diabetes, hypertension) also contributed to infant mortality among AI/AN. Birth certificate data indicate AI/AN are more likely to have less than twelve years of education, twice the rate for non-natives; single marital status also contributed to infant demise. Single mothers, or mothers who did not list a father's name were more likely to have low birth weight infants (Blabey & Gessner 2009). Other contributions to infant mortality identified were late or no prenatal care (Castor et al. 2006).

Health disparities among minority AI/AN children, where SIDS is also the leading contributor to infant mortality, plague American Indian communities across the nation (Baldwin et al. 2008; Castor et al., 2006; Gaudino, 2008; MacDorman 2011). The

highest incidence of SIDS among AI/AN occurred among AI in the Midwest. Kvign et al. (2008) studied the use of alcohol among pregnant AI and found binge drinking associated with SIDS. Halloran and Alexander (2006) discussed the relationship of SIDs, low-birth weight and potential environmental triggers that could contribute to mortality and morbidity.

Health Care Providers, Pediatric Environmental Health Competencies, and Education

In 1993, a landmark report was published by the National Research Council entitled *Pesticides in the Diets of Infants and Children.* The report ushered in a series of protective recommendations including regulatory policy changes and acknowledged the unique age-related susceptibilities of infants and children. In 1995 the Institute of Medicine (IOM) report *Nursing, Health & the Environment* was published and under the watchful eye of Florence Nightingale, nurses were encouraged to return to their roots with this statement: “The environment is one of the primary determinants of individual and community health . . . unfortunately, most health care providers, including nurses, are inadequately prepared to identify or respond appropriately to such hazards or conditions” (pp. 1-2). The IOM report identified environmental health hazards and suggested specific recommendations to enhance nursing practice, nursing education/professional development, and nursing research.

In 1999, the Children’s Environmental Health Network published the *Training Manual on Pediatric Environmental Health: Putting It into Practice* that included a faculty training guide, strategies and tactics for teaching, and information on advocacy,

developmental stages, epidemiology, as well as modules on childhood lead toxicity, metals, air pollution, and solvents. This work launched the pediatric environmental health (PEH) educational effort but failed to ignite curricular changes in nursing and medical schools across the country. In the meantime, researchers and policy advocates continued efforts to investigate and document excess morbidity, mortality as well as the economic impacts of pediatric health hazards (Brent & Weitzman, 2004; Landrigan et al., 2002; Woodruff et al., 2004).

Finally in 2004 the National Environmental Education and Training Foundation (NEETF) created a position statement that addressed the need for "environmental education for health care providers, especially physicians, nurse practitioners, physician assistants, nurses, nurse midwives, and community health workers who work at the frontline of the health care system" (Rogers, 2004, p. 154). The specific statement included the following ideas:

Therefore, The National Environmental Education & Training Foundation (NEETF) recommends that professional associations, decision-making bodies, academic institutions, and practice settings of health care providers endorse the need to address health conditions associated with environmental exposures, and:

- Adopt environmental health education and practice skills standards so that health care providers learn and integrate information about environmental exposures in clinical, educational, and preventive health care activities.
- Incorporate clearly defined environmental exposure educational competencies and practice skills, including the ability to elicit an environmental exposure history, into health care provider education and practice.
- Use validated tools and resources available through an array of mechanisms, such as professional journals, newsletters, central internet

sites, and professional meetings to recognize, manage, and prevent health effects from environmental exposures.
- Appoint an environmental health "faculty champion" at each medical and nursing school to ensure long-term integration of environmental health content into medical and nursing school curricula.
- Update requirements to include the recognition, management, and prevention of health effects related to environmental exposures in medical, nursing, and other health care provider education.
- Promote incentives for faculty to teach core competencies, including financial incentives in the form of grants, faculty development, curriculum development, and research; instructional teaching and training aids; expert consultants; clinical access; release time for faculty development; curricula development; and establishing appropriate clinical sites and teaching venues.
- Facilitate access to environmental health continuing education programs (Rogers, 2004, p. 155).

The Faculty Champions Initiative, an evaluation research study sponsored by NEETF, was launched and tested with 28 pediatric health care professionals participating in a train-the-trainer event. Participants, were charged with "increase(ing) the number of health care professionals able to address children's environmental health issues into practice and integrat(ing) identified pediatric environmental health competencies into medical and nursing practice and curricula" (Rogers, McCurdy, Slavin, Grubb, & Roberts, 2009, p. 851). The goal of the project was to create faculty champions who were proficient in five competency areas:

1. Taking a pediatric environmental health history;
2. Making referrals for preventive and curative interventions for possible environmental health hazards;
3. Being involved with community groups/organizations regarding risk communication;
4. Identifying resources used to address pediatric environmental hazards;
5. Reporting incidents for regulatory requirements (p. 851).

The convenience sample of participants were from diverse geographic areas and included 15 physicians, seven nurse practitioners, five nurses with graduate degrees, and

one physician assistant with a doctoral degree; 15 males and 13 females. Participants completed a workshop evaluation, an action plan, a pretest and two posttests, baseline data and progress assessments, and two telephone interviews. This initiative was judged successful 12 months after the initial workshop when the first and second posttest results improved significantly from the pretest average score of 52% to 65.5% and finally 71.5% respectively. Ninety percent of the participants were able to accomplish curricula integration at their institution. A total of 1559 health care professionals (345 physicians, 750 nurses, 464 other professionals) were trained by the faculty champions, exceeding the goal of 280 (Rogers et al., 2009). This action-oriented model for curricula integration successfully achieved the goal of this initiative by implementing the position statement for health professionals and environmental health education (Rogers, 2004).

Other local or regional efforts to determine environmental health educational needs of health care providers are documented. An educational needs assessment of attitudes, beliefs, and practices of health care providers (pediatricians, nurse practitioners, physician assistants) was launched to investigate the health effects of pesticide toxicity. Information was collected from participants living in and around the Washington DC area through questionnaires and focus groups. A total of 64% of practitioners and 69% of nurses described feeling unprepared for patient questions about pesticides. The study results established the need for more pesticide education for health care providers. Continuing education preferences among providers included lectures and short courses (Balbus, Harvey, & McCurdy, 2006). Providers today, five years later, might choose different modes of delivery possibly involving new technologies.

A cross-sectional survey was conducted by Hill, Butterfield, and Kuntz (2010) to determine barriers and facilitators to incorporating environmental health into public health nursing practice. Although a bachelor's degree is required for public health nursing (PHN) in many states this study was conducted in a western state where approximately 30% of the PHN workforce holds an associate degree in nursing or less. Some of the barriers to incorporating environmental health into practice included: "few or no resource people with expertise" in this field (12%); "little or no time to include the topic into clinical practice" (20%); and "clients/families have little interest in understanding how the environment can affect health" (15%) (p. 125). When asked to think about "what would facilitate or help you to address environmental health issues in your nurse practice" the top three responses included (a) free or inexpensive continuing education programs (66%); (b) the internet and other workplace resources (63%) and, (c) access to a staff resource person who is knowledgeable in this area (54%) (p. 126). This study although non-generalizable to public health nurses does provide a glimpse of the challenges of incorporating environmental health into clinical practice. Although no specific issues related to children were raised in this survey, responses such as "no time" "no one is interested" "no resources" sheds light on the urgent need for more education regarding the public health impacts associated with environmental exposures.

Another survey of health professionals conducted in the Pacific Northwest found a training gap among physicians, physician assistants, nurse practitioners, and community health workers who serve in pesticide-intensive agricultural areas. Approximately 92% of the respondents to a telephone survey indicated a need for pesticide information related to

exposures in children. Web-based materials, written summaries, and conference/workshop formats were the most common continuing education preferences (Karr, Murphy, Glew, Keifer, & Fenske, 2006).

Shendell, Alexander, and Huang (2010) developed an environmental health priorities survey for school nurses to determine their ability to identify and prioritize asthma triggers. The small sample size prevented testing for statistical significance but the average participant scored 80% on the posttest. The tool developed by Georgia State University Institute of Public Health was comprehensive and could be used as an assessment and information tool by other school systems.

Yet another approach to health care provider education approach presented by Betz and deCastro (2010) used an existing case study to introduce nurse practitioner students to childhood pesticide exposure and risk assessment. Shendell and Pike-Paris (2007) utilized a "primer" approach by publishing an "environmental hot topics" article to "enhance knowledge and awareness of the basic concepts of human exposure assessment" for pediatric nursing professionals (p. 179). The information article provides an in depth overview of sources of environmental pollution along with emissions data to better understand air quality. This type of presentation targets those who generally read a specific journal in this case, *Pediatric Nursing*.

The thirteen Pediatric Environmental Health Specialty Units (PEHSUs) established across the U.S. serve as another resource for families and health care professionals. "PEHSUs provide services to families, act as consultants to clinicians and public health agencies, develop educational materials, and respond to natural disasters

including hurricanes and wildfires" (Paulson, Karr, Seltzer, Cherry, Sheffield, et al., 2009, p. 5511). The three primary functions include: "educating health professionals and others about issues; consulting about known or suspected exposures . . . and providing referrals to environmental health specialists" (p. 5512).

Both physicians (Etzel, Crain, Gitterman, Oberg, & Scheidt, et al., 2003) and nurses now have the promise of environmental health competencies embedded in curricula. In 2010, the American Nurses' Association updated *Nursing: Scope and Standards of Practice*, added Standard 16: Environmental Health and specific competencies for both the registered nurse and the advanced practice nurse. These competencies specifically address an issue that had previously gone unmentioned.

Standard 16: Environmental Health Competencies for the Registered Nurse

1. Attain knowledge of environmental health concepts, such as implantation of environmental health strategies.
2. Promotes a practice environment that reduces environmental health risks of workers and healthcare consumers.
3. Assesses the practice environment for factors such as sound, odor, noise and light that negatively affect health.
4. Advocates for the judicious and appropriate use of products used in health care.
5. Communicates environmental health risks and exposure reduction strategies to healthcare consumers, families, colleagues and communities.
6. Utilizes scientific evidence to determine if a product or treatment is a potential environmental threat.
7. Participates in strategies to promote healthy communities.

Competencies for the graduate-level prepared specialty nurse and the Advanced Practice Registered Nurse:

1. Create partnerships that promote sustainable environmental health policies and conditions.
2. Analyze the impact of social, political, and economic influences upon the environment and human health exposures.

3. Critically evaluate the manner in which environmental health issues are presented by the popular media.
4. Advocate for implementation of environmental principles for nursing practice.
5. Support nurses in advocating for and implementing environmental principles in nursing practice." (ANA Scopes and Standards, 2009, p.61-62)

In summary, environmental health as a subspecialty is not a new topic but only in the last 20 years have competencies for specific health professions (physicians, nurses, advanced practice nurses, physician assistants) been developed . Educational needs assessments exist for a broad range of providers but there is still a need to assist providers to determine their knowledge, skills, and attitudes (competencies) regarding general topics and specific toxins. A variety of environmental health delivery modes are documented in the literature including the use of self-study modules, conferences, case studies, consultation, and primers/CEU units in professional journals. Despite these efforts, a knowledge deficit also described as a health literacy challenge (Shendell et al., 2010) may exist in current health care providers who received their professional education prior to curricular integration and for those who have not had the opportunity to stay up-to-date on the current literature on environmental toxins.

Toxins, Exposure Pathways, and Pediatric Susceptibilities

Environmental toxins pose a serious health threat to children around the world. The World Health Organization (WHO) has estimated that as many as three million children under the age of five die each year due to environment-related disease (WHO, 2011). Children in undeveloped countries often endure much of the disease burden. For instance, one study of children who live in the slums of Niarobi found that dramatic shifts

in weather along with exposure to indoor air pollutants such as smoke and kerosene were associated with higher incidence of pneumonia (Ye et al., 2009). It is difficult to link single exposures to single disease outcomes so for this reason Briggs (1999) developed the Multiple Exposures Multiple Effects (MEME) model that "emphasizes the complex relationships between environmental exposures and child health outcomes . . . (and) the contextual conditions, such as social, economic, or demographic factors" (WHO, 2011, p. 1). This model supports the indicators necessary to monitor health in children: exposure, outcomes, context, and action.

Much of the pediatric environmental health literature include expert opinion articles that summarize current literature (Brent & Weitzman, 2004; Goldman et al., 2004; Landrigan, et al., 2002; 2011; Woodruff et al., 2004). Without longitudinal studies like the National Children's Study (2011), current research relies on epidemiological studies that attempt to link exposures (air quality) to a condition such as asthma (Mohai, Kweon, Lee & Ard, 2011; Sheffield, Roy, Wong, & Trasande, 2011) and small studies of local exposure (Postma, Butterfield, Odom-Maryon, Hill, & Butterfield, 2011). Often researchers target a specific toxin such as mercury (Lincoln et al., 2011; Lee at al., 2009) or environmental tobacco smoke (Anderko, Braun, & Auinger, 2010; Singh, Siahpush, & Kogan, 2010). Exposures, due to some type of pollution, can be summarized based on the type of source--either natural or human-caused (anthropogenic) (Shendell & Pike-Paris, 2007).

One excellent source of evidence-based risk assessment related to specific contaminants is the Collaborative on Health and the Environment (CHE) (2011), a

searchable database. “The CHE Toxicant and Disease Database summarizes links between chemical contaminants and approximately 180 human diseases or conditions” (p. 1). Because of the complex interactions between toxins and disease, determining cause and effect relationships is difficult. This website catalogues and rates evidence as “strong” “good” or “limited/conflicting.”

To better examine relevant exposures, Table 1 summarizes sources of six common contaminants that have been scientifically linked in the literature, to health effects in children. This short list represents a few contaminants that would fall into the “all health care providers should know” category.

Table 1: Common Exposures: Sources/Route, Health Effects, and Prevention

Chemical	Source/Routes	Health Effects	Prevention
Lead	Paint, dust, water, soil/ingestion	Brain and nervous system damage; bevioral/learning problems; hearing problems, headaches, slow growth	• Avoid lead paint dust • Be aware of lead pipes • Avoid lead products
Mercury	Fish/ingestion Hg vapor/air	Neurological development, cognition, thinking, memory, attention, language, fine motor/visual spatial skills	• Fish advisories • Use tuna and mercury calculators • Thermometer recall
PCBs*	Mother’s diet/ ingestion (fish, milk)	Possible human carcinogen, immune system suppression, low birth weight, learning deficits	• Select lean meat • Low/nonfat milk • Observe fish advisories
ETS**	Tobacco smoke/ prenatal, postnatal	Asthma, SIDS, lung cancer, nasal sinus cancer, respiratory infections,	• No smoking inside buildings and cars • Education
BPA***	Chemical compound used to harden plastics/prenatal	Endocrine-disrupting chemical that affects neurologic and behavioral early life development.	• Be aware of BPA in canned food lining • Plastic food wrap
Pesticides	900 products use to kill insects, weeds, mold, rodents/air, water, food.	Acute poisoning, rash, respiratory, neurologic effects/hyperactivity, birth defects, mutations, leukemia, lymphomas, brain cancers	• Wash fruit & vegetables • Use organic methods and products • Remove shoes worn outside

Adapted from Sattler & Davis, 2008; Physicians for Social Responsibility, 2008
*PCBs (Polychlorinated biphenyls) **ETS Environmental Tobacco Smoke ***Biphenol A

Lead. Landrigan et al., (2002) and the team's expert panel determined lead exposure in children was 100% attributable to the environment. Toxic effects included "cognitive changes, behavioral changes that may produce increased rates of criminality, drug abuse, and incarceration (as well as) cardiovascular disease" (p. 723). Lead exposure in children is an intensely studied toxin. Wigle (2003) presented the "chronology of lead" (p. 72) with the 1943 discovery of lead as a neurotoxin. It was not until 1978 that the Environmental Protection Agency (EPA) banned lead-based paint. The Center for Disease Control and Prevention (CDC) has set the action level for lead at >10 µg/dl (CDC, 1997). Karr (2008) identified the role of primary care providers in primary, secondary, and tertiary prevention and provided a resource for practitioners testing or following children with elevated blood lead levels. Karr stated, "Given the limited medical interventions to improve the outcome of children with exposure to lead and increasing appreciation of the potent neurodevelopmental neurotoxicity of lead, the importance of primary and secondary prevention are underscored" (p. 755).

Mercury. "Humans are exposed to methylmercury through food (especially fish) . . . both the maternal body mercury burden and current exposure are major mercury sources for the fetus because mercury can pass through the placenta and blood-brain barrier" (Jiang, 2010, p. 518). Risk assessment studies around the world have identified women, infants, and children at risk for mercury exposure (Jiang et al., 2010; Kuntz et al., 2009; Lincoln et al., 2011; Ricco, Anderko, & Anderson, 2008). Since fish, contaminated through anthropogenic processes (emission from coal-fired power plants), serve as the primary route of exposure, fish monitoring and advisory programs are in

place across the U.S. (Kuntz et al., 2010). However, unlike other toxins that are clearly hazardous with no merits (asbestos, lead, environmental tobacco smoke), the clear "benefit" side of fish consumption creates a risk communication challenge for providers. Clearly a neurotoxin at high exposure levels (Harada, 1995), low dose exposures can pose a significant hazard in the developing brain (Genius, 2008). Health care providers should be aware of local fish advisories and national efforts to reduce exposure by eating "safe" fish.

PCBs. "Monsanto, the sole manufacturer of PCBs in the U.S., produced about 700,000 tons during the period 1929-1979 . . . given their high heat capacity and stability, PCBs were ideal for uses in heat-resistant solvents, sealants, and lubricants" (Wigle, 2003, p. 136). Although no longer manufactured, PCBs remain a ubiquitous environmental toxin, still remains in the food chain, and is linked to neurodevelopmental toxicity in the developing fetus. Park, et al. (2010) studied a cohort of 750 children in Slovakia who were evaluated for PCBs through cord serum samples and later underwent developmental testing using the Bailey Scales of Infant Development-II. Results indicated that the PCB exposed children preformed more poorly on the developmental tests. Health care providers can best advise clients to minimize exposure by selecting lean meat, low or non-fat dairy products, and to be aware of local fish advisories for PCBs (Wigle, 2003).

ETS. The risks to infants and children related to environmental tobacco smoke (ETS) are well established with exposure outcomes linked with sudden infant death

syndrome (SIDS), asthma, and behavioral problems in older children (Brim, Rudd, Funk, & Calahan, 2008; Carlsson, Johansson, Hermansson, & Andersson-Gare, 2009; Dietert, DeWitt, Germolec & Zelikoff, 2010; Jarvie & Malone, 2008; MacDorman, 2011; Ruckinger et al., 2010). Attitudes regarding smoking around children and in public places have gradually shifted in the past ten years with the majority of adults (smokers and non-smokers) supportive of smoking bans (McMillen, Winickoff, Klein, & Weitzman, 2003). However, American Indian and Alaska Native populations continue to be overrepresented on several infant mortality measures (SIDS, pre-term births) associate with ETS (MacDorman, 2011). A study conducted in Sweden found that although nurses are confident in their tobacco prevention roles and responsibilities and have access to evidence-based practice tobacco prevention programs, there is a need for "continuous education and training in communication skills to reach vulnerable groups" (Carlsson et al., 2009, p. 507).

BPA. Bisphenol A has been used to make plastics since 1940 and today, "seven billion pounds of BPA are produced annually, with more than two billion pounds produced in the U.S" used to make baby bottles, plastic drink bottles, microwave products, and liners for canned beverages, fruits and vegetables (Erler & Novak, 2010, p. 400). BPA is an endocrine disruptor and while not as diethylstilbestrol (DES) that was taken off the market some years ago, the product is known to increase prolactin release and stimulates uterine, vaginal, and mammary growth (Vandenberg et al., 2010). Animal studies have demonstrated an increase in mammary cancer susceptibility in offspring after oral prenatal exposure to BPA (Betancourt, Eltoum, Desmond, Russo, &

Lamartiniere, 2010). In one case, a woman with a high BPA concentration and her offspring were followed to determine the neurological outcomes. A transient behavioral effect was noted but the lesson learned from this case was the exposure route (high intake of canned beverages and canned vegetables) and the windows of susceptibility during the prenatal period. The case points to "a potential link between gestational BPA exposure and transient neurobehavioral changes" and the need for future studies (Sathyanarayana, Braun, Yolton, Liddy, & Lanphear, 2011, p. 1170).

Pesticides. The unique characteristics of the developing fetus and child including immature detoxification systems and water and food intake per unit of body weight differences, put children at increased risk for adverse effects from pesticides. "Conventional pesticides comprise a diverse group of substances intended to destroy, repel, or control organisms . . . such as insects, fungi, or plants" (Wigle, 2003, p. 162). The health effects associated with pesticide exposure and children include a wide range of systems (reproductive, endocrine, neurodevelopmental, and immune) (Gilden, Huffling, & Sattler, 2010). In one study, children were tested for urinary levels of organophosphate metabolites and those with higher levels were more likely to be diagnosed with attention deficit hyperactivity disorder (Bouchard, Bellinger, Wright, & Weisskopf, 2010). The widespread use of pesticides compels health care providers to include health history questions regarding potential exposure in children (Gilden et al., 2010).

Other Toxins of Concern for Children's Environmental Health. In addition to physical toxicants, recent literature point to the importance of determining the impacts of social toxicants and psycho-social stress as well. The interactive effects of not just demographic factors, but identifiable social toxins (violence, poverty, and economic barriers of parents and their children) should be factored into the equation (Wright, 2009). The National Children's Study (2011) has adopted a model that complements the Multiple Exposure Multiple Effects model (Briggs, 1999) with the inclusion of factors including psychobiologic measures and gene-environment interactions (Dietrich et al., 2005). It is increasingly difficult to find single factors (mercury, PCBs, or lead) that can be definitively linked to specific conditions since prenatal and postnatal influences are complex (MacDorman, 2011; Wright, 2009).

Theoretical Framework: Translational Environmental Research in Rural Areas (TERRA)

The TERRA framework addresses environmental health risk and perception of risk in a "rapidly evolving body of science addressing environmental health and environmental justice" (Butterfield & Postma, 2009, p. 107). For this study concepts from the TERRA framework were applied to assess the perceptions of local experts, health care providers on one Northwest tribe, in regards to their understanding of local environmental health risks toward the fetus, infant and child. In addition, competencies and educational needs regarding pediatric environmental health were addressed. The

TERRA model guided the study in terms of the rural setting in which environmental health was being evaluated.

Macrodeterminant

The macrodeterminants of the TERRA framework focus on, “physical-spatial, economic resources, and cultural-ideology” (p. 109). The framework applies to this study in terms of the rural setting of one Northwest tribe. TERRA also considers the cultural determinants present, which is imperative as this study encompasses a culturally significant group. Lastly, the TERRA model reflects on the economic resources that have the potential to determine response to environmental health. The TERRA framework allows for local input to evaluate risk; as self perception of risk will depict how one will respond to environmental risk reduction.

Inequities

The TERRA framework addresses inequities confronted by rural communities. Rural communities have differences in “income, race/ethnicity, economic vitality and health access issues compared to urban areas” (Butterfield & Postma, 2009, p.111). The concept of inequities is adapted to this study in terms of the population being surveyed and the geographic location, as well as the culturally diverse group in which the data pertains. This study addresses how local health care providers perceive health disparities and environmental health issues among the area and the population they serve. Regional data depict health disparities among AI/AN children including fetal, infant and child mortality and morbidity (USDHHS 2008). Also, health care providers are challenged by

the rural characteristics, therefore in order to have an impact on minimizing the gap of health care disparities, educational needs related to improving competencies in pediatric environmental health must be addressed.

Environmental Health Risk

TERRA refers environmental health risk to “the potential of an agent to induce a health problem”. This concept is adapted to this study in terms of evaluating health care providers perception of risk in the local area in which they practice.

Environmental Health Mental Models

The TERRA framework also evaluates how risk is perceived. Personal thoughts and feeling toward risk influence resolution of how environmental health can impact them. Knowledge is power in terms of risk perception. In terms of this study, health care providers must be aware of potential risks that influence the health of their community. Therefore, this study evaluates local health care provider’s knowledge, perception and educational need on pediatric environmental health.

Environmental Risk Reduction (ERR)

TERRA addressed ERR “based on informed decision-making approach” (Butterfield & Postma 2009, p. 113). The premise of this study was to provide local health care providers with information on pediatric environmental health and how the understanding of this information could impact the health of the fetus, infant and child. Based on their understanding, health care providers were asked to evaluate their community and personal experiences with PEH. They were asked to identify cause of

mortality, morbidity, and potential environmental exposures that could be harmful to the fetus, infant and child. Lastly, they were asked to evaluate their education needs and preferences on this topic. This process brought awareness of the topic and allowed for co-understanding of the community, and educational needs of health care providers.

Timing and Elements of Environmental Risk Reduction Interventions

TERRA addressed ERR "based on informed decision-making approach" (Butterfield & Postma 2009, p. 113). The premise of this study was to provide local health care providers with information on pediatric environmental health and how the understanding of this information could impact the health of the fetus, infant and child. Based on their understanding, health care providers were asked to evaluate their community and personal experiences with PEH. They were asked to identify cause of mortality, morbidity, and potential environmental exposures that could be harmful to the fetus, infant and child. Lastly, they were asked to evaluate their education needs and preferences on this topic. This process brought awareness of the topic and allowed for co-understanding of the community, and educational needs of health care providers.

Outcomes

The TERRA framework utilizes the approach that in order for an issue to be addressed, the information about that issue needs to be prominent and relevant. TERRA differentiates outcomes proximally and distally. Proximal outcomes are generated out of "beliefs of EH, self perception and enacting risk reduction behavior and the continued practice of ERR" (Butterfield & Postma 2009, p.113). In this study, health care providers

are presented with information about environmental health and the potential effects they can have on the fetus, infant and child. Potential hazards and health outcomes are presented along with information that addresses preventative measures. In a focus group forum health care providers are evaluated for their beliefs and understanding of pediatric environmental health in their local area of practice, by identifying causes of mortality and morbidity, addressing potential environmental hazards and finally addressing educational needs.

Distal outcomes are defined in terms of, “an increase in ERR and a decrease in the number or level of abnormal exposures” (Butterfield& Postma 2009, p. 114). The premises of this study surmise that awareness and education of health care providers on pediatric environmental health issues will incorporate measures that will facilitate long-term outcomes of ERR and exposures that potentially attribute to the health disparities of AI/AN children.

Theoretical Framework: Community Based Participatory Research (CBPR)

Community Based participatory research is a method of research the bridges the interest of the academic researcher and the community. CBPR builds lasting community partnerships in order to minimize health disparities by investigating the needs and issues of individual communities. The purposes of conducting CBPR include: establishing trust, sharing power, foster co-learning, enhance strengths and resources, build capacity and examine and address community-identified needs and health problems. Establishing trust can be accomplished by building partnerships with community resources that might have

interest in the study (Shoultz et al., 2006). The culture of the community must be considered as a component when building trust, without such regard communities can feel exploited. This can be accomplished by identifying community needs. (Shoultz et al., 2006). In order to enhance strengths and resources, local resources can be combined to work on a research project, which can also facilitate purposes of shared learning and capacity building (Shoultz et al., 2006). Isreal et al. (2010) captured purposes of trust, shared power and enhanced strengths and resources by partnering with two long-term local agencies that shared an interest in the public health of their community. By training local community members in policy advocacy, Isreal et al. (2006) fostered capacity building by providing information that could empower individuals which in turn builds capacity in the community.

CHAPTER 3

METHODS

Introduction

The primary goal of this study was to utilize local expertise to identify potential environmental exposures on one Northwest reservation and county that could put the fetus, infant, and child at risk for excess morbidity and mortality. A pediatric environmental health conference designed for health care providers was held on January 29, 2010. This conference served as the platform for both continuing education units for health care providers and data collection for this study. A qualitative, community-based participatory research design and focus groups were used to investigate the following questions:

1. What are the perceptions of health care providers regarding environmental hazards that could affect fetal, infant, and child morbidity/mortality?
2. What are the potential environmental health issues that could impact the fetus, infant, and child on the reservation-of-interest?
3. What are the health care provider educational needs related to improving competencies in pediatric environmental health?

The methodology employed to investigate the research questions is presented in this chapter. The chapter is organized in seven sections: (a) population and sample, (b) design, (c) procedure for data collection, and (d) instrumentation, (e) discussion of human rights and consent process, (f) data analysis, (g) summary.

Population and Sample

The research participants were purposively selected. Health care providers were recruited from a Northwest tribal health organization and the local county public and private health agencies. Forty participants were chosen from approximately 100 registered pediatric environmental health conference attendees. Participants representing a variety of health care specialties (e.g. physicians, nurses, community health representatives, public health workers) were invited by research team members familiar with the local tribal and county workforce. Participants were selected based on their knowledge of the population, availability, and interest in attending the day-long environmental health conference including the two-hour focus groups held at the end of the day. In addition to the free conference and continuing education credits, each focus group participant was awarded an honorarium for their contribution to the study. To assure each focus group was adequately populated, a waiting list was generated from the conference attendee list. All conference attendees registered online through the Eventbrite © website. Demographic data and contact information were collected electronically and conference reminders were sent just prior to the event.

Design

A descriptive, naturalistic, qualitative research design was used for this study. Qualitative data were collected by way of focus groups. The study incorporated a community based participatory approach by tapping the expertise of directors of Tribal Health and Human Services and County Public Health to identify and engage potential

participants. The directors selected health care providers that were able to discuss the subject of pediatric environmental health based on their experience with and knowledge of the local community.

The use of qualitative, naturalistic research design allows the researcher to study the human experience of the phenomena of interest. Qualitative research relies on the collection and analysis of narrative and subjective data. Naturalistic research can elicit rich in depth information that can potentially provide a variety of diverse data related to the research questions (Polit & Beck, 2008). Complementing the naturalistic approach, community based participatory research engages community members regarding the dynamics, resources and issues of importance to the community. Additionally, this approach establishes trust and fosters co-learning among community experts and academic investigators (Christopher et al., 2008; Strickland, 1999a). Since, the goal of this study was to identify potential pediatric environmental hazards on one Northwest reservation from the health care providers' perspectives; it was also possible through this community engagement event, to query health care providers' perceived educational needs on pediatric environmental health topics.

The focus group data collection process is a method in which a group of people who have knowledge of the subject matter are brought together by the researcher in order to elicit rich experiential data on a topic. Participants of focus groups can be chosen purposefully or randomly, depending on the intention of the study. Participants should possess commonalities that are determined by the purpose of the study. In the case of this study, we purposefully selected health care providers who were currently practicing

their professions on or near the Reservation. The literature varies in regards to group size. However, the research does suggest that "groups should be small enough to allow all participating members an opportunity to share, while large enough to gather a diversity of perceptions" (Krueger & Casey 2009, p. 6). Focus groups are led by a moderator. The roles of the moderator are to promote discussion on the subject matter by following a predetermined set of sequential questions. The moderator should encourage participation from all members of the group and keep the discussion on track (Asbury, 1995). The questions are open-ended and should incorporate a natural flow to allow for a candid discussion of participant perceptions (Krueger & Casey, 2009). Focus groups are commonly audio recorded therefore the venue in which the sessions are held should be considered for their acoustic quality. Lastly, "a note taker should be present to document field notes and observations" (Strickland, 1999, p.191).

Procedures for Data Collection

The application to conduct the research was deemed exempt and approved by Institutional Review Board from Montana State University and the local tribal college, since no individual identifiable data were collected. The forum for data collection took place at the Pediatric Environmental Health Conference on January 29, 2010. Participants were invited to be a part of the conference and focus groups by community partners/members of the research team who were familiar with tribal and county health care providers. Interested attendees registered to attend the Pediatric Environmental Health Conference online. The designated password protected registration website was

located at http://www.evenbrite.com . During the electronic registration process, demographic data were collected including the attendees name, address, telephone number, age, number of years in practice, level of education, field of practice and previous training/education in pediatric environmental health. The first 40 invited participants to register had the opportunity to be a part of the focus groups. Continuing education credits were available to all who attended the conference, including those who agreed to participate in the focus groups at the end of the day.

All conference attendees were asked to complete an anonymous pretest and posttest the day of the conference to determine level of before/after knowledge regarding pediatric environmental health issues. In addition, focus group participants were informed of the purpose of the study, expected role as a participant, and provided an informed consent form during registration (Appendix B).

Asbury (1995) defines focus groups "as a data collection technique that capitalizes on the interaction within a group to rich experiential data allowing the researcher to gain an enlarged sociological and psychological understanding of the lived experience" (p. 414). Focus groups and inclusion of a wide range of invited health care providers allowed for a broad range of input from different geographical regions across the reservation (Kreuger & Casey, 2009).

According to Asbury (1995) groups should consist of six to12 individuals who are similar in some way. The forty participants in this study were from a variety of health care backgrounds, and assigned to one of five groups of eight individuals. A focus group facilitator guided the discussion based on a prescribed protocol (Appendix C). The focus

groups were each assigned a group leader, also known as a moderator. The roles of the moderator were to ask the questions to the group encourage discussion from all group members and keep the discussion on track as it pertained to the study. (Asbury 1995). Each focus group leader for this study had a background in health care, followed a semi-structured interview guide using a list of 12 questions (Appendix A).

Since each participant's identity was not disclosed, to ensure rigor and validity of the instrument (Appendix A) the focus group leaders clarified responses during the focus group discussion. In order to minimize alteration of data, the group leader utilized probing questions and statements to ensure data were interpreted in terms the participant meant to express the information. Asbury (1995) notes the importance of documenting non-verbal behaviors or other dynamics that cannot be gained from audio recording. Therefore, individuals who were non-participating focus group members were assigned to take notes in each group. Annotations were also taken by a roving direct observer who captured group behaviors and interactions and environmental factors.

Instrumentation

The literature advises that the creation of a new instrument should be an option of last resort (Polit & Beck 2008). However, no instruments were found to fit the need of the research data desired for this study. The research tool (Appendix A) utilized was modified using some of the concepts of Trasande (2006), and was specifically designed to meet the needs of this study. Therefore pretesting of the instrument was necessary. The literature advises that an instrument should be piloted for several reasons: "a)

determine the clarity, b) identify wording that could be offensive, c) determine if the sequence of the questions are sensible, d) determine training needs of moderators, and e) determine whether the instrument produces sufficient variable data" (Polit & Beck, p. 380). Since focus group sessions should not be longer than two and half hours (Krueger & Casey, 2009), the instrument was also critiqued for time as advised in the literature (Polit & Beck 2008).

The research tool consisted of a semi structured questionnaire with 12 open-ended questions in four categories. The questions allowed for creative input from participants on their perceptions of environmental health and infant mortality/morbidity related to pediatric environmental health. Participants were also asked about their environmental health education needs.

The tool (Appendix A) was initially developed by the research team then modified by the investigator. The research team is made up of an academic nurse researcher from Montana State University, a graduate student, and community partners from a northwest reservation, the community health director of the tribe, as well as faculty from the local tribal college and the county health department director. Their role was integral in assisting with guiding the research process and providing local expert knowledge of the community. The tool was piloted with a health care professional/educator to determine the clarity of the questions and to check for content validity. Lastly, the instrument was revised and then reviewed by the Environmental Health Advisory Committee (EHAC) to ensure the tools ability to capture reliable and culturally appropriate data. The EHAC provides proposal to publication guidance for

researchers embarking on environmental health research one Northwest reservation. Activities include reviewing research proposals, research methods, and procedures, providing feedback on research proposed, and cultural perspective related to research methods and findings. The committee normally meets once a month for one-two hours and is provided information to review in advance of the meeting. Although it is not possible to adequately pay community members for their cultural and community knowledge contribution, a $50.00 honorarium is given to members for each meeting attended.

Discussion of Rights of Human Subjects and Consent Process

Participants in the focus group were consented the day of the conference prior to the focus groups. The consent form (Appendix B), provided information on the purpose of the research, compensation, procedures, risks/discomforts and benefits related to their participation. The consent informed participants that audio recordings would take place during the focus group sessions. Each participant was assured that confidentiality would be maintained. The consent provided a clause that offered each participating member to withdraw from the research at their discretion. An honorarium was provided to participants for their time and input.

The focus groups were audio recorded but no comments were identified or attributed to specific individuals since participants did not reveal their identity during the data collection process. A professional transcriptionist with human subject's protection training was hired to transcribe the audio files.

Data Analysis

There are multiple ways of conducting qualitative data analysis using focus groups. The goal of qualitative data analysis is to "organize, provide structure and find meaning from the data collected" (Polit & Beck 2008, p. 507). The purpose of the study guides the analysis process to effectively and efficiently gather the data of greatest value to the research. Purpose driven analysis also prevents the researcher from getting lost in details. (Kreuger & Casey 2009). Data for this study was transcribed by a professional transcriptionist who developed a record and saved it in a Microsoft word document. Data was then reviewed by the investigator and further reviewed by members of the research team and will eventually be reviewed by EHAC.

Data analysis was conducted by reviewing the audio recording transcription of the focus group discussions. This investigator for this study manually conducted content analysis from the transcribed audio record of each of the five focus groups. Categories were established using the twelve-question tool (Appendix A) from the focus group interview. The initial content analyses was overseen by the principal investigator of the project and reviewed by the research team. A follow-up step will involve sharing the initial themes of this study with the EHAC who will provide additional cultural background and insights and guide the use of language, interpretation and dispersal of research finding (Cashman 2008). Initial themes were organized into potential findings of the health care provider's perceptions of environmental health. Next, environmental hazards and exposures and there potential effects on infant mortality among the American Indians in the area were identified as well as the perceived pediatric environmental health

education needs of health care providers. In follow-up to this thesis, the data will be returned to the community for further comment and elaboration, first to the EHAC, then to the elders, and finally to specific focus group members. This process will give greater meaning to the results and will guide next steps.

Summary

This chapter described the process for collecting and analyzing the data for this study. In order to identify health care provider perceptions on environmental health and infant mortality and morbidity among American Indians, a qualitative descriptive design was utilized. Forty individuals were consented and then participated in focus groups led by trained facilitators. The focus group questions (Appendix A), participant consent (Appendix B), and facilitators protocol (Appendix C) can be found in the appendices.

CHAPTER 4

RESULTS AND ANALYSIS

Introduction

The purpose of this study was to gain a local perspective from health care providers regarding pediatric environmental health issues and perceptions of how the fetus, infant and child on one northwest reservation and the surrounding county might be affected by hazardous environmental exposures. Qualitative content analysis was conducted on data gathered through focus groups convened following a pediatric environmental health conference. Narrative data were transcribed and reviewed to identify common themes that portrayed a local health care provider perspective of potential environmental exposures that place the fetus, infant, and child at risk for excess morbidity and mortality. Additionally, health care providers were queried to discover educational needs and support systems that might help address pediatric environmental health issues in everyday practice. The research questions answered in this study were:

1. What are the perceptions of health care providers regarding environmental hazards that could affect fetal, infant and child morbidity/mortality?
2. What are the potential environmental health issues that could impact the fetus, infant and child on one Montana Indian reservation and surrounding county.
3. What are the health care provider educational needs related to improving competencies in pediatric environmental health?

Each of the forty health care providers (HCPs) selected to participate in one of the focus groups (eight individuals per group), attended a five-hour environmental health education conference prior to the focus group event and received 5.5 continuing

education credits for the pediatric environmental health content. A total of five focus group discussions were recorded, transcribed, and analyzed. Moderators, followed a written protocol (Appendix C) to guide participants through a total of twelve questions (Appendix A) nested in three categories; health care provider perceptions (three questions); environmental health issues (six questions); and, health care provider educational needs (three questions). The focus groups were engaged in a discussion that provided rich experiential data about the local community. Out of the five groups, four of the groups were able to address all 12 questions presented by the moderator in the two hour time period. The information provided a local perspective of how one community reflects the findings of other research studies concerning hazardous environmental exposure issues. Primary themes were assessed based on topic frequency. Table 2 summarizes the primary themes for each question. In addition, a category entitled "other pertinent information" allowed inclusion of insightful discussion points that were unique but less frequently discussed. Kreuger and Casey (2009) describe the importance of "knowing a gem when it comes along" (p. 121).

Table 2: Primary Content Analysis Themes

Focus Group Question	Top Three Themes	# of Comments
Health Care Provider Perceptions		
1. When I hear the phrase "environmental health" I think of . . .	• Community • Safety • Toxins	(14) (11) (6)
2. As a health care provider, what do you perceive as the leading causes of infant/child <u>mortality</u> in our area?	• SIDS • Lack of Education • MVA	(12) (10) (4)
3. As a health care provider, what do you perceive as the leading causes of infant/child <u>morbidity</u> in our area?	• Lack of Resources • Weight Management • Safety	(10) (10) (8)

Table 2: Primary Content Analysis Themes - Continued

Environmental Health Issues		
4. What possible environmental health issues could impact the health of the fetus, infant, or child? Of this list, which are the top three issues?	• Drugs/Alcohol • ETS • Methylmercury	(8) (5) (4)
5. In what ways are health care providers involved with pediatric environmental health issues in our area (reservation and county)? How can a health care provider's involvement be enhanced?	• Education • Prevention • Resources	(15) (11) (9)
6. What are the barriers to enhancing/adding environmental health to a health care provider's practice?	• Lack Priority • Fiscal • Cultural	(20) (8) (7)
7. What interventions are needed to protect the fetus, infant, or child from environmental hazards?	• Education • Resources • Laws	(17) (5) (4)
8. What do you see as gaps in policies at the tribal, county or state levels that would provide protection to infants and children from environmental health risks?	• Lack of consistent laws (ETS) • Lack of agency coordination/collaboration • Lack of Primary seatbelt law	(6) (5) (4)
9. Is there an existing group or resource in our area that could be utilized to address/follow/advocate for pediatric environmental health issues? Explain.	• Tribal Council • Tribal Health • FICMR	(3) (3) (2)
Health Care Providers		
10. What educational methods would be most helpful to improve health care provider competencies in pediatric environmental health? What topics regarding pediatric environmental health would you like to learn more about?	• Conferences • Webinars • CEU/Curriculum • Electronics • Chemicals • Effects of exposure • Substance Abuse	(7) (4) (4) (4) (3) (3) (1)
11. Earlier we discussed community-based participatory research (CBPR). How might a busy health care provider be involved with CBPR on the reservation?	• Provide Data • Participate in Research Process • Identify Problems/Needs	(8) (4) (2)
12. Today we focused on health care providers perception's of pediatric environmental health. Which individuals or agencies not here today, could provide information that would enhance our knowledge of pediatric environmental health on the Flathead Reservation/Lake County?	• Law Enforcement • Tribal Environmental Health • Primary Care Providers • School Officials	(4) (3) (3) (3)

Demographics

Focus group attendees were purposely selected local health care providers. The health care professional participating in the focus groups consisted of physicians, nurses (tribal, county, and hospital), WIC personnel, community health representatives and sanitarians. The majority of the participants were nurses. All participants were currently active in practice from one to 16 years. The breakdowns in the number of years in practice were as follows: one to three years were 34 %, 4-10 years were13 % percent, 11 to 15 years were 11 %, 16 or more years were 30 %. Forty percent of the focus groups were employed by the tribe, while the other sixty-percent were from other local health groups around the county. Also, of the focus group participants, 42.5 % had tribal affiliation. Among those participants claiming tribal affiliation, 76.4 percent were from the local tribe and 23.5 percent were from other tribes. Lastly, upon registration 85% of the attendees indicated they had never received formal training in pediatric environmental health.

Research Question 1: Health Care Provider Perceptions

The first research question of this study was, “What are the perceptions of health care providers regarding environmental hazards that could affect fetal, infant and child morbidity/mortality?” Three discussion questions were asked to produce data to address this inquiry.

Focus Group Question 1

The first focus group question, "When I hear the phrase 'environmental health' I think of…" was discussed by all five groups. The topics and number of times each theme was mentioned is found in Table 3.

Table 3: Question 1 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Community	1	1	12	0	0	14
Safety	0	1	5	2	3	11
Toxins	0	1	2	2	1	6

The first open-ended question was phrased to begin the discussion among participants. Each participant was asked to finish the statement based on their own ideas and perceptions. There were three goals to the opening question. The first goal was to introduce the topic to be discussed. The second goal was to use the phrase as a mechanism to engage participants in discussion so that they could build confidence and reassurance that their input was greatly valued. Lastly, the opening phrase provided insight into the views of each participant on the subject matter -- environmental health (Kreuger & Casey, 2009).

There was little variation among the focus groups with this question. Each moderator directed the question to the group and in a circular fashion allowed each participant to share their thoughts and ideas. Almost all respondents provided one term answers with very little discussion. In two of the five groups, participant responses produced group member discussion. This question was answered by 100% of the

participating focus group members. Question one elicited a wide array of responses. Among all groups there were 13 themes captured. The top three themes most frequently discussed across all groups were: community, safety and toxins.

Community. The topic of community often pertained to where people lived and functioned and included: culture, school environments and home environments. In terms of culture several participants discussed how culture influences how people live and form values. One participant discussed environmental health in terms of the people who live on the reservation.

> It makes me think of not only the physical environment but environment created by culture.

> I see environmental health as one of our dimensions in the triangle of environment, agent and host. Environmental factors whether social, economical, where we live, or culture, play a role and (are a part of the) process in disease states and whether we acquire a disease from everything from water, from how deep our wells are, to economic factors, to where we live as far as where our jobs are, . . . everything in the environment has a significant impact on our health.

Along with community, groups discussed the home and school environments related to environmental health. Participants discussed how the environment of a child whether home or at school affects the health of the community as a whole.

> For me, when I think of environmental health and coming from a public health stand point it is so wide and is such a broad spectrum. Doing home visits (and) looking at the home environment--looking at pretty much everything within the household and things going on with all parties living in the homes . . . looking and dealing with the schools . . . I work with prenatals, newborns up to dealing with death and dying. Looking at the environmental for me is looking at the home environment and people in general.

> I think about what's in people's homes and how they can live a healthy life and pass on to their children . . . sanitation practices and things that newborns and moms and pregnant moms just need to (know about their) environment to keep things safe and healthy for their family.

Safety. The second most frequently discussed theme was that of safety. This topic was captured a total of 11 times in four of the five groups. Participants commented that they perceived safety as an environmental health factor in terms of child safety, household safety diet, and child supervision at home and at school.

> The one word I'm thinking of I wouldn't say disaster, but you know safety, probably.

> For me, the environmental health of children is social/economic definitely. Did they come from a warm house last night? Did they come into their classroom needing food? Maybe they haven't eaten since lunch the day before when they were in our classroom? Are they going to go home to their parents or are they going to go home to a daycare because parents are working? What's in those homes? What kind of toxins? Is it safe? How old is the house? How deep is the well? Is it a common well? What things are being tested? If the home hasn't been tested then how old is the home? That kind of stuff. Going home to a grandparent's home that maybe medications aren't safely stored. It's a variety of factors. Where are they going? Where did they come from? What's the next step before and after they are in our facility?

> I just think of safety in our living.

Toxins. Toxins were the third most frequently captured theme in relation to perceptions of environmental health. One participant mentioned only the term toxins but did not go into a detailed response. Along with toxins, the word "chemicals" was mentioned. Other terms grouped under toxins because they were not expanded upon included pollution, as well as specific elements such as lead, and mercury. Mercury was

mentioned in relation to a local reservoir by one participant and in fish by another participant.

> Mercury levels in the Noxon Reservoir.
>
> Methylmercury and fish.
>
> Before I came to this conference, I thought mostly of lead exposure and things like that . . . . not so much (about) some of the social things that are involved. (The conference) broadened my horizons a bit.

Other Pertinent Themes. Although some themes were not discussed as often as the top three, many of them were very pertinent to the topic of environmental health. Water and air quality were each mentioned in three of the five groups. Air and water quality are pivotal concepts to environmental health in terms of the health and well being of humans.

> I think the place we live in, the water that we drink, the air we breathe.
>
> When I think of environmental health, I think of poor communities…somewhere bigger than this state, somewhere there is absolutely no health care and nothing at all. But then after attending this conference you can see that it is definitely right in your own communities…when you look at it (environmental health) in more depth, you look at the whole person and why they are that way and what parts of their life environmentally affect their health

The ecosystem was mentioned once and the participant gave valuable insight into her understanding of its relevance to environmental health.

> When I think of environmental health I think of our surroundings; the air quality, the forest, whether animals are allowed to live or die. Like reintroducing the wolf into a place where they have cattle that (the wolf) is naturally going to go for and then saying that they are bad because they attack cattle. . . . the environment and the wellbeing of the whole world, the earth, the health of everything, the surroundings.

Finally, risk was another theme that was mentioned by three participants in two different groups. Risk is pertinent in relation to environmental health in terms of identifying potential harm to those in the environment as well as determining interventions.

Risk factors for our children.

My first thought was actually risk…

When I hear environmental health I think of risk and prevention.

Question one, although limited in detail, captured the participation of group members that was needed to elicit more discussion for the remaining questions. The question also allowed the moderators to gain group trust in order to continue to gather more data for the other topics to be addressed.

Then next two questions under the umbrella of health care provider perceptions were asked in order to evaluate participant knowledge of mortality (death) and morbidity (defined as illness or disease) of the fetus, infant and child in their area.

Focus Group Question 2

The second focus group question, “As a health care provider on this Northwest Reservation/County what do you perceive as the leading causes of infant/child **mortality** in our area?” was discussed by all five groups. The topics and number of times each theme was mention is found in Table 4.

Table 4: Question 2 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
SIDS	0	3	5	3	1	12
Lack of Education	1	0	3	3	3	10
MVA	0	1	1	1	1	4

Focus group question two was asked to gauge participant knowledge of local mortality incidence. Since the participants are in a unique position as practicing health care providers, this question was aimed at gathering data on this topic via their personal perceptions of what might be occurring in the local area.

For this question, moderators followed the protocol which resulted in little variation in how the question was asked of each focus group participant. The question was answered by 100% of the focus group members. The top three themes generated from this question were sudden infant death syndrome (SIDS), lack of education and motor vehicle accidents (MVA).

SIDS. All groups agreed that the leading cause of death on the reservation and within the county was from SIDS. This theme was discussed among all five groups. It was mentioned approximately12 times. One participant discussed their role in reviewing infant deaths in the local area and the leading cause of death due to SIDS. Another participant discussed infant mortality most often associated with babies being placed in inappropriate places to sleep such as, couches, adult beds or with poor bedding. Along with SIDS, groups elaborated on contributing factors. One group discussed how

substance abuse, such as alcohol, and drugs contributed to the risk of a child dying as a result of SIDS. Another participant commented that many of the infant/child deaths in the area may not be attributed to SIDS but instead be labeled as "unknown." However, a common trait associated with the deaths is often environmental tobacco smoke (ETS). Socioeconomics was also mentioned as a contributing factor to SIDS because parents may not be able to afford a living environment that places a child in a safe sleeping place.

> …a couple of thing come to mind for me, when reviewing infant/child mortality in the county one of the biggest factors is SIDS, but what happens a lot of the times here is a death will be listed as undetermined. It won't get that SIDS definition or classification. Also, I would say that safe sleeping environments and smoking (or secondhand) smoke in the household are two big major factors that seem to come up in a lot of the infant deaths in the county.
>
> One thing that we found was that there was a consistent death pattern in babies that were placed in inappropriate places to sleep; couches, adult beds, poor bedding. Safety issues, lack of education, maybe lack resources to buy a crib or have access to a crib.
>
> The data says most of the time our mortality comes from unidentifiable causes, but we also know that some of the unidentifiable causes are those social situations that people find themselves in… how lack of a safe sleeping environment may be due to living with others, homelessness.
>
> I'm agreeing with the issue of parents not being able to afford proper sleeping equipment. A baby sleeping with their parents is also cultural for some people. So yes (SIDS) can be associated with cultural or socioeconomic causes . . ."

Lack of Education. The second most common theme pointed to an indirect or related cause of infant/child mortality--a lack of education. This theme was discussed in four of the five groups and mentioned approximately 10 times. The lack of education was most commonly discussed in terms of maternal education. The groups discussed a young

mother's ability/inability to understand fetal development and how to remain healthy and minimize risk to the developing fetus.

> I also think a contributing factor is our young mothers, our teenage mother and the environments that they are living in, and the lack of education concerning prenatal care, neonatal care, a healthy and nutritional diet, (and the risk of) smoking and alcohol.

One participant used the term, "Babies having babies" to describe what she sees as a risk factor of young mothers who lack essential education.

> It is not that the health care is not there, they (young mothers) just don't know where to go get it or they may not know it's available.

> . . . lack of parental education can result in neglect because a parent doesn't know when to bring their child to the doctor . . . I see in my school setting parents that don't take their children to the doctor when they have ear infections… and (the children) are often not being cared for dental health wise as well.

> I feel that a lot of these younger girls don't have enough education and the support to help them go get their prenatal care or other resources that are available on the reservation to help them have a healthy baby.

Motor Vehicle Accidents. The third most common theme discussed related to infant mortality was that of motor vehicle accidents. This theme was discussed in four of the five groups and was mentioned approximately four times. Within in this theme, group discussion was related to motor vehicle safety and the lack of caregivers using preventative methods to keep their children safe.

> We are doing better educating (parents) about the proper use of car seats but you still see the kids standing up next to the parents, and riding in the back of pick-up trucks or running around all over the car. We need to continue to do more on preventions, as these are preventable deaths.

Participants also mentioned that a person's economic situation may determine a caretaker's initiative to utilize proper motor vehicle safety. One participant commented that her patient did not have a car or a car seat for her toddler, so instead, strapped her child in an adult seatbelt.

Other Pertinent Information. Among the discussion of mortality, some participants discussed how culture impacts ones' beliefs and how they choose to care for themselves or their children. Cultural influences, was mention in three of the five groups, and referred to approximately four times. For example something scientifically found to be harmful, such as ETS may not be depicted as "bad" and caregivers may not see a need to remove a child from such an environment.

> I also agree that it is cultural; it is peer pressure, if you look at the age group and grandparent involvement, attitudes can include statements such as, 'we smoked around you and you were fine' -- they just don't have the knowledge but the information is out there.
>
> In Native American culture, we like to do what our other families did because things were good, but what they don't realize is that things have changed so much and that we have access to this research.

Lastly another cultural issue discussed was that of Native American families who do not want help from non-natives; therefore they may miss out on resources that could benefit their children.

Other pertinent discussion points that came from the groups included ETS and substance abuse topics.

> I also think it has a lot to do with the smoking in the house. I mean a lot of kids get respiratory infections like pneumonia and they (the children) are susceptible to so many things and if (the parents) were educated, they

> could prevent or at least modify (some or all) of the exposure their children receive.
>
> I think neglect…parents not being aware of what's going on due to being high on pills or high on drugs… these younger parents come in all wasted.

Another person recalled a child's accidental death directly linked to caregiver substance abuse.

Finally, there were many facets of infant mortality in the local area that focus group members found important to share. The common denominators included SIDS, lack of caregiver education, MVA's and substance abuse including ETS, drugs and alcohol. The discussion points intertwined with the safety of the infant and child. One participant summed up her thoughts and ideas about infant mortality in these words.

> It really takes a village to raise a child and when there is a disconnect in the village system, the inexperienced young person does not have a role model to follow, making it difficult for younger generations to create a safe environment.

Focus Group Question 3

The third focus group question, "As a health care provider on the Northwest Reservation/County what do you perceive as the leading causes of infant/child **morbidity** in our area?" was discussed by all five groups. The topics and number of times each theme was mention is found in Table 5.

Table 5: Question 3 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Lack of Resources	2	2	5	1	0	10
Weight Management	4	4	2	0	0	10
Safety	0	0	0	3	5	8

This focus group question was asked to gain insight on local morbidity issues. There was little moderator variation with this question, except for one group that elaborated extensively on their thoughts. All five focus groups addressed this question.

The participants discussed many aspects of morbidity. With this question it was hard for participants to focus on symptoms, diseases, or illnesses. The groups focused more on contributing factors. As a result 13 themes were captured. The top three themes discussed included resources, weight management and safety. This section will also elaborate on other pertinent themes related to morbidity.

Resources. Resources were discussed among four out of five of the groups. The theme was mentioned approximately four times with the topic discussed in terms of lack of or inappropriate resources. Under resources focus groups discussed socioeconomics of families and their ability/inability to afford necessities to keep themselves healthy such as health care. Comments characteristic of this theme include the following:

> You know if you are in an environment in which you are young and have a little one and you can't find a way out and your parents are not responsible and you are 15 years old and pregnant or have a baby, I think maybe you don't know who to turn to always… so I am thinking a lack of knowledge about resources available for support.

> It is really hard to be thinking about getting a child to the doctor if you are thinking-we don't even have gas money to get to our WIC appointment to get milk.

One group discussed how they feel that more and more people are putting off accessing health care to avoid having to pay a bill. As a result people are much "sicker" when they finally access care. Another group commented on the limited health care resource of tribal health care and Indian Health Service (IHS).

> Federal prisoners have better health than people who use IHS.

The discussion continued to reveal the member thoughts about misconceptions about tribal health and IHS by the public.

> People don't understand (the tribal health or IHS system), I hear them say- "Oh your tribal health"- what they don't understand is the limited services provided at the clinic. If you need a certain medication-if it doesn't fall within being one of the cheapest medications, but it has ten side effects, it doesn't matter that is what you get. No matter who you are or what tribe you come from the service is the same. At the college I have to say to some of the people; have you ever been to an IHS? Have you actually walked in and looked at what goes on…IHS is just not what people think it is and it is sad.

> It doesn't matter if you have tribal health or IHS, if you have a condition that does not get approved for surgery or whatever than a person must go without the care needed. Restrictions have been getting progressively tighter with IHS for the past ten to fifteen years. It has been harder and harder to get health care.

Another topic related to access to resources was that concerning dental health. Groups have identified that dental decay among children is a serious morbidity issue in the area. One group discussed how it is difficult to access dental care for prevention, because the dentists are too busy caring for secondary and tertiary dental disease in children. The groups discussed how parents need to be educated early about dental care,

because a lack in self dental care results in many children needing dental surgery to treat severe dental disease.

Lastly, concerning resources, one group discussed the heightened awareness of some parents seeking out various forms of health care coverage. The group discussed how parents are seeking a diagnosis for their children that would make them eligible for public resources such as Medicaid or social security. They have seen this practiced in parents with children who may have health problems like cleft palate, because they don't have health insurance or they do not trust the IHS or tribal health services to cover their child's need for specialty care.

Weight Management. The theme of weight management was discussed in terms of obesity, improper diet and sedentary or lack of exercise/activity. This theme was brought up in four out of six of the groups. Groups discussed how the conveniences of today have impacted the health of children by promoting more sedentary lifestyles, poor nutrition and an increase in obesity. The groups also discussed how parents are no longer role modeling active lifestyles because they are also immersed in a lifestyle of conveniences. One participant commented on how children are no longer socially interactive with people, their environment or the earth. Instead, children of today are more immersed in the ease of technology, video games, television and computers.

> (Children) are experiencing a world that is just very different from what we are historically used to (encounter).

Weight management was also discussed in terms of proper diet. Once again, participants discussed today's fast, convenient lifestyle and how these realities have

changed the dietary habits of young people. Groups discussed how the most accessed foods are also the most affordable. They discussed how socioeconomics determines how healthy a child will eat due to the fact that the more nutritious foods are also the most expensive.

Another group discussed how weight management and obesity affects the mental health of a child. One participant commented on how parents are bringing their children into the doctor to get a medical excuse from attending their physical education classes. Children who are obese do not want to attend physical education because they are not able to perform some of the maneuvers that are expected. As a result of the inability to perform, children become embarrassed, either because of their own self consciousness or other children making fun of them. The child's embarrassment has the potential to lead to depression or other behavioral problems.

Safety. Safety was the third most discussed theme related to morbidity. Safety was discussed among two out of five of the groups. Participants discussed the topic in terms of motor vehicle safety, household safety and neglect of children due to parental age, socioeconomics or substance abuse. Regardless of the issue, participants agreed that the lack of supervision places a child at risk for injury. One participant commented on motor vehicle safety.

> I think general safety, For instance, not properly retraining children in child seat.
>
> There are so many people driving around with their children jumping around in the back seat. Also, adults are not wearing seatbelts, so they are not setting an example for children, who grow into adults that don't value seatbelt use.

Participants discussed how substance abuse of parents or caregivers impacts the morbidity of a child.

> Alcohol and drug abuse. When parents are suing drugs or alcohol they are not paying attention to their children. They (the children) are passed off to somebody else to care for them, sometimes that can be an older sibling that may only be 10-11 years of age.

In another example a participant discussed that college student single mothers often bring their children to their college classes which was thought to be a safety issue since the mother was more focused on the class than her child/children.

> I notice a lot of times that some of the young moms have to bring their children to school because there is no daycare or other support systems to help care for their children. . . (sometimes) two to four children attend class with them.

Finally, another participant commented on home safety, such as a child accidently ingesting lethal doses of a cleaning product or medication.

Other Pertinent Information. Among the discussions, one group discussed the lack of immunizations placing children in the community at risk for communicable disease. The groups stated that there are many factors in the current area that may lead to under or over immunization. First, the reservation has a large transient population. Most commonly this is related to students attending college. Therefore; parents don't always know where to access care for immunizations. There are many avenues in which a child can become immunized in the local area (doctor, community health nurse, public health nurse, at school, or a sports event). As a result, confusion arises when a parent uses multiple agencies to immunize their child.

> We have a real mobile population… there are a lot of extended family and people bouncing community to community… or household to household, … we do not technically have a homeless population, because those without homes are usually staying in a household of someone they know.

Secondly, despite the availability of a state and tribal database for documenting immunizations, the system is not always current, since it is up to each individual agency to record immunizations into the database there are various factors that hinder this process.

Research Question 2: Environmental Health Issues

The next six questions were written to capture perceptions of area health care providers regarding local environmental health issues. In this section, questions were asked about local environmental health issues that have the potential to be harmful to the fetus, infant and child; the involvement of health care providers on environmental health issues; barriers to practice; interventions; and, gaps in policy. There was moderator variability present in this section of the discussion but four out of five of the focus groups addressed all of the questions.

Focus Group Question 4

The fourth focus group question, "What possible environmental health issues one Northwest Reservation/ County could impact the health of the fetus, infant, or child? Of this list, which are the top three issues?" was discussed by all five groups. The topics and number of times each theme was mentioned is found in Table 6.

Table 6: Question 4 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Drugs/Alcohol	2	1	2	2	1	8
ETS	1	1	1	1	1	5
Methylmercury	0	1	0	1	2	4

There is a potential for any area of the reservation or county to have environmental health issues that could impact the health of the fetus, infant or child. The purpose of this question was to have the groups identify what they perceived to be the top three issues. From the perspective of the health care providers, the top three issues were drugs/alcohol, environmental tobacco smoke, and methylmercury. This question was answered by all of the focus groups. Nevertheless, moderator variability was present with one moderator not stating the question exactly as it was written; however, the group was still able to answer the question.

Substance Abuse. Drugs/alcohol was the top theme captured among the focus groups. The theme was mentioned eight times and it was discussed in all of the groups. Groups suggested that substance abuse was a basis for causing problems for the fetus, infant and child developmentally and behaviorally. One person stated how the effects of methamphetamine can be known immediately, however, the effects of alcohol may take years to manifest.

> The whole home is the foundation and if you have alcohol in your home then everything else is out the window from there, diet, your life, and your stress.

> I agree with alcohol, we have a few children that come into WIC with fetal alcohol syndrome and neglect.

Along with substance abuse, participants discussed the environmental effects of methamphetamine labs and the unknown exposures related to them.

> My concern is what we are in putting in the environment with crank labs, is it a toxic waste that is going to poison our babies.
>
> We don't see as many meth labs as we did five to ten years ago, but we don't know the ramifications to those who live in or who were exposed to the production of it.

Environmental Tobacco Smoke. Environmental tobacco smoke was the second most common environmental health issue the groups discussed. The topic was mentioned approximately five times and was discussed in all five groups. Participants talked about the prevalence of exposure. One participant discussed how there is a large population that uses smoking tobacco. As a result children are exposed in the home, vehicles and at the immediate doorway.

> There is nothing more annoying than seeing a pregnant woman standing outside smoking a cigarette.
>
> I think it goes back to smoking, we see mothers going out to smoke two hours after delivery or a caesarian section…it's just a matter of picking your battles.

Finally another person elaborated on the toxins created by cigarette smoke:

> . . . fifteen-percent goes to the individual, and eighty-five percent goes to second hand smoke then third hand smoke . . . (and) the lingering chemicals that fall onto clothes, furniture and carpet … . .yet you still see a mom with a bus load of children with her window cracked smoking a cigarette.

One group discussed the increased prevalence of asthma and a participant added the following comment.

> I think ETS is a huge problem and we are seeing a lot more asthma as a result.

The focus groups also discussed local policy issues regarding ETS. Since there are two existing policy makers in the area, the tribe and the county, the anti-smoking policy is not consistent. Currently, local tribal policy does not support smoke free buildings in some tribally owned businesses such as the casinos, restaurants and bars. Although, smoking is not allowed in most tribal buildings, it is not discouraged near the doorways, and some buildings have designated indoor smoking areas. As a result, many participants voiced how one is exposed to smoke indoors because of the lingering smoke at the doorways.

> At the fitness centers people want to light up right out the doorway and their smoke is lingering into the building where people are exercising and they get offended by asking them to smoke away from the entry into the parking lot.

Methylmercury. Methylmercury was the third most discussed theme in regards to local environmental health issues. The theme was discussed in four out of five of the groups. Methylmercury was mentioned approximately four times. Although participants listed methylmercury as a local issue, there was not much elaboration on the topic. Two groups listed the theme as an issue, and two briefly commented on how they were enlightened about the topic even though the interpretation of the message was not completely accurate. This observation points to the importance of risk communication

accuracy for both health care providers and the public. Women of childbearing age are advised to eat 6-12 ounces of safe (low mercury) fish per week.

> . . . the information on mercury levels in the fish and how women of child bearing age should not eat it fish more than once per month…that is pretty significant I think.

Another person discussed how economically feasible it is for younger families to eat fish from the local waters because it is free and easily accessible.

> I would think that would have some impact on a pregnant woman if she is eating the fish…

> …today they (the conference speakers) mentioned the fish, that sound like it's a major issue in the area, it's in the food banks, I think it is great for the area that they figured out which fish to eat.

The lack of elaboration on this topic by the groups is characteristic of health care providers who might be aware or recently aware of an environmental health issue while lacking specific or in depth information.

Other Pertinent Information. Another theme that came up frequently was that of pesticides. Pesticides were mentioned in three out of five of the groups. The groups discussed the active agricultural community in the area.

> …And there are a lot of potato farmers in the area and so everyone has the big pivots on all these fields, and flowing from the aquifer and the chemicals bin is right at the base of those pivots and so every time the watering goes that's all a part of that contamination.

Others added to the discussion by mentioning crop dusting with the planes that fly across the land spraying chemicals. Another person expresses how children are exposed to pesticides through water contamination.

> We are big water users here in the area and a lot of pesticides runs off into the rivers, lakes and ditches. The children are exposed to chemicals and pesticides while swimming and recreating in the waters.

Indoor/outdoor air quality was also mentioned in terms of carbon monoxide and forest fires. Participants described the challenge of living in an area where the winters are cold and many people use wood stoves to heat their homes. One group discussed the forest fire smoke in the summer and how they are also affected by smoke from fires that occur in the Missoula, Kalispell and Washington area. One person added that they see more people with respiratory problems in the summer months due to the heavy smoke levels.

Focus Group Question 5

The fifth focus group question, "In what ways are health care providers involved with pediatric environmental health issues in our area (reservation and county)? How can a health care provider's involvement be enhanced?" was discussed by all five groups. The topics and the number of times each theme was mentioned is found in Table 7.

Table 7: Question 5 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Education	7	3	3	0	2	15
Prevention	2	2	1	3	3	11
Resources	0	2	4	0	3	9

Question five was asked to get participants to think about what was occurring as far as a health care providers' involvement in pediatric environmental health and how their involvement could be enhanced. The question was asked consistently among all of

the groups. However, there was some moderator variation in how the question was asked. Some moderators chose to address the two part question separately; one group discussed the first part of the question but did not address the second part. At this point in the discussions, the focus groups seemed to be comfortably immersed in providing input and readily responded to the question and to each other. There were eight themes captured. The top three themes discussed among the groups included: education, prevention and resources.

Education. Education was mentioned in terms of educating oneself, other health care providers, children and other individuals, or organizations that dealt with expectant mothers and their infants and children. The theme was discussed in four out of five of the groups and was mentioned 15 times. Groups discussed how they thought that well child exams were a perfect opportunity not only to survey for potential exposures but also to provide age-appropriate education to the parents of a child. One group discussed how every clinic visit should be utilized to provide pediatric environmental health information; stating especially older children because they do not usually go to the doctor except for a sports physical or acute illness. Groups also agreed that outside of well child clinics, there are plenty of other sources that could provide education including the schools, Headstart, WIC, and prenatal classes.

> I do home visiting so I get some hands on and get to see the environment the children are living in. I would like to be able to enhance my visits by increasing my knowledge. I would be able to give them so much more.

One individual discussed how health care providers are entering the schools to present education on tobacco prevention. Another group discussed how they are utilizing a grant to educate expectant or new moms on SIDS prevention.

Prevention. Prevention was the second most discussed theme in regards to health care providers' involvement in pediatric environmental health issues. Prevention was discussed in four out of five of the focus groups and mentioned approximately 11 times. Groups discussed how prevention takes place in different ways including, awareness of potential environmental hazards for both the health care provider and parents, taking children to routine medical check-ups and keeping immunizations current. Some participants discussed how health care providers could make an environmental assessment as part of their usual routine with any type of patient encounter, such as, clinical or home visits. They discussed how a health care providers' participation in the education and prevention programs can enhance involvement. One participant stated that involvement could be enhanced by being aware and knowledgeable of the latest issues and information available. Participants found prenatal programs as a favorable method of prevention because these types of programs help to get information out early, ensuring healthy development at the fetal stage. Prenatal programs also help parents find resources, improve parenting skills and allow for assessment and early intervention of the home environment to maintain the health and well being of an infant's and child's development.

> We also have prenatal classes that we offer in each community…Once we find out that you are pregnant, if a person chooses to come in and visit with the nurse, what we do is have them come in, we set up a time to

> provide education about what to expect (with pregnancy and infant care). Then we go into their home and assess the sleeping environment for the baby, availability of a carseat, we also do a postnatal follow up visit.
>
> I think that tool (environmental assessment) would be a really great thing especially because so many of the environmental toxins can have a profound, long-term, neurological affects that are so insidious. I think it's really important that children's environments are being assessed…

Resources. Resources were the third most discussed theme concerning health care provider involvement in pediatric environmental health issues. Resources were discussed in two out of five of the groups. Resources included the lack of manpower in relation to the provider patient ratio and were needed in order for communication and coordination to become more effective. Financial need to keep resources was also mentioned. One participant discussed how they are able to provide incentives to pregnant women who follow through with their prenatal program. The incentives help accomplish a few needs of the program. First they keep participating moms motivated to complete and follow through with the program. Secondly, the incentives supply a need to the expectant mom such as baby furniture and clothing. However, these types of programs are only kept going based on available funding. Therefore, if the fiscal needs of a program are not met, the service will end.

> I think one of the biggest things that come to mind is money--where are we getting the funding to be able to buy incentives for first time moms. I think that funding can be a hindrance in providing information.
>
> For my department, there are only six people covering a whole reservation, we don't see only pediatric patients, but we care for elders, diabetes and a whole barrage of other tasks. There are just not enough hours in the day to do everything.

One group discussed communication and coordination of resources.

> I think on the reservation we have a lot of resources for people to access, we just need to work more closely together so we can cover everyone.
>
> Yes I agree with coordination. Sometimes we don't know about a pregnancy until after a patient delivers . . . a better means of communication could help so that more moms can have healthy babies.

Another participant discussed how educating health care providers on resources available and what they do will enhance communication and coordination. The groups agreed that "networking and communication" was key to health care providers being involved in pediatric environmental health issues in the area.

Other Pertinent Information. Culture was discussed two times in two out of five of the groups. The discussion of culture is pertinent because participants acknowledged how culture was important to approach and should be considered in providing information. Participants thought relaying pediatric environmental health messages in a culturally sensitive manner was critical since the message would be better received and more likely practiced. Participants felt it was important that parents not feel threatened or made to feel bad because this would only hinder progress and relationship between families and the health care system.

Focus Group Question 6

The sixth focus group question, "What are the barriers to enhancing/adding environmental health to a health care provider's practice?" was discussed in four of the five groups. The topics and number of times each theme was mentioned is found in Table 8.

Table 8: Question 6 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Lack of Priority	4	2	0	4	10	20
Fiscal	1	2	0	0	5	8
Cultural	3	2	0	0	2	7

The purpose of this question was to have focus groups consider what they do now and evaluate existing barriers to enhancing or adding environmental health care to their current practices. This question was asked by moderators in four out of five of the focus groups. The groups came up with five themes including priority, fiscal, cultural, transportation, and accessibility to patients.

Priority. Priority was discussed in 80% of the groups. The theme was mentioned approximately 15 times. Priority was the most discussed barrier to enhancing or adding environmental health to practice. Priority was discussed in terms of time, work load and urgency of the task. One group discussed how in most health care settings, the volume of patients, commonly outweighs the number of staff available so the most urgent issue takes precedence, and teachable moments are often lost. Another person described how a clinic visit usually only allows for 10-15 minutes; it takes the entire time to figure out the problem and establish a plan of care. Unless the environmental issue is the primary complaint, it will not likely get addressed in a primary care setting.

> Of all the providers I have worked with, they usually rely on the public programs, like public health and WIC to provide environmental health information.

> You have to put out the biggest fire first. It does seem like time, money and work force or the lack of work force would be big barriers…If you have something that is screaming for your attention you are going to have to deal with that first, then you can deal with environmental assessment, because that is a smaller fire…
>
> I agree that doctors only have fifteen minutes with a patient, so they have to prioritize their visit. I think environmental things are toward the back and I they (providers) have had very much education on environmental factors with health. They see so many people that they have to focus on one thing, whether it is diabetes or a cold.

Finally, one group discussed environmental health being a priority to parents.

> You can't teach a mom while she is trying to quiet this baby and get another to settle down. It's not a teachable moment so you have to find time where you can teach.

Fiscal. A lack of financial resources was also a theme the groups discussed. Financial resources were discussed in three out of five of the groups. The lack of fiscal resources affects how business is done. Leadership "buy in" is necessary, because it is the leadership that allocate where financial resources are distributed. If pediatric environmental health is not seen as a priority, fewer resources will be available to address such issues.

Cultural Issues. Culture was the third most captured theme as a barrier to enhancing/adding environmental health to health care practice. The theme was discussed in three of the five groups and was mentioned approximately 15 times. Culture was discussed in terms of ethnicity of the patient, patient/community readiness and patient/parent readiness to learn. One group discussed how there are times when health

care providers are not able to give a message in a culturally appropriate manner therefore; they will avoid the discussion.

> …I just heard an elder say, they are still trying to convince us that these cigarette are bad for us. . . . This type of situation would be difficult for a younger educator to understand.

Another person discussed how some cultures don't make eye contact and how that might seem to the educator as disregard for the information being presented, when in actuality this is an act of listening. Culture also determines an individual's readiness to learn. One example given was that of methylmercury. If a person does not eat fish, they might not be interested in learning about the issue.

Other Pertinent Information. Transportation and access to patients was also discussed in terms of a barrier to implementing environmental health into practice. Participants discussed how living in a rural area some residents live long distances from the health care services, therefore they are not always able to come to health care sites. They also discussed how there is limited public transportation in the area. One person discussed how the tribe has recently broadened their public transportation system. As a result, participants discussed how they are hopeful that the increase in available transportation will make health care more accessible. Another barrier discussed was that of locating patients in need. Due to the large transient population, patients can be difficult to locate as a result, referrals are difficult to fulfill. Also with this population, stated contact information is seldom current. So many times patients are searched for through other agencies, or if known, friends and family.

Focus Group Question 7

The seventh focus group question, “What interventions are needed to protect the fetus, infant or child from environmental hazards?” was discussed by four of the five groups. The topics and number of times each them was mention is found in Table 9.

Table 9: Question 7 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Education	3	5	0	6	3	17
Resources	2	1	0	0	2	5
Laws	2	1	0	0	1	4

Participants were asked their opinion about interventions to protect the fetus, infant and child from environmental hazards. All groups were fairly consistent with their ideas. This question was answered among four out of five of the groups. The top three themes were: education, resources and laws.

Education. Education was the most common theme discussed. The intervention was discussed among all the focus groups who were asked the question. The theme was mentioned approximately seventeen times. Groups discussed how education to the community, parents and self promotes awareness of environmental health issues. It was the belief of the group that the more a person knows about potential harms and dangers the more likely they are going to practice prevention. One group discussed how health fairs were an inclusive means of providing education.

> I think the interventions are centered around education, including, education as to the dangers of smoking when you're pregnant, why prenatal care is important, and the importance of a healthy diet.
>
> . . . education can break cycles of unhealthy behaviors and decrease potential harm caused by exposure to environmental harms.

Groups also discussed how health care providers should not assume the knowledge is there. Groups used examples of environmental tobacco smoke and repeat pregnancies as common examples where health care providers might assume the patient knows more than they do. Groups also discussed how education with "hard evidence" and "tools" has a greater impact than verbal instruction alone. Examples of education "evidence and tools" included videos, real life stories, demonstration (child restraints), and pictures.

> I really get a reaction from people when I display my picture book of rashes; it provokes questions and opens up an educational opportunity.

Resources. Having available resources to address pediatric environmental health issues was the second most discussed theme as a means of intervention. Resources were captured among three out of five of the groups and were mentioned approximately five times. The groups discussed how the right resources could provide a "safety net to the unborn" such as early prevention and education. The groups discussed how the local area has resources available to meet such needs, but the issue can be getting the resources to the patients who need them. Referrals were one method discussed as far as getting resources to those who need them.

> I think once a woman is found to be pregnant, she could be involved in a full coordination of resources including, WIC, public health, home visiting and childcare.

> I think they are all such good services and could do so much to prevent and monitor at the early stages, it's just a matter of access by the patient or to the patient.

Finally, the groups discussed how available resources can improve healthy relationships, improving self-esteem and decreasing stress.

Laws. Laws were the third most discussed theme in terms of interventions that could keep the fetus, infant and child protected from environmental hazards. The theme was captured in three out of five of the groups and mentioned approximately four times. The groups discussing laws, talked about how either new laws or stricter enforcement of laws could serve as interventions. Currently, there are no laws in place to protect a fetus. Despite the fact that in-utero is where the effects of exposure has a vast impact, there is no law to intervene and prohibit potential harm.

> When you see a pregnant woman using alcohol, even in excess, there is nothing you can do to protect the unborn.

The groups discussed how the lack of a primary seatbelt law needs to be changed in order to better enforce child restraint use in moving vehicles. Along with enforcing laws, one person discussed how driving under the influence (DUI) is impacting pediatric environmental health.

> I would like to see better enforcement of DUI's. I think fallout from a DUI affects the kids, the families, generations.

Other Pertinent Information. Some participant discussed how advocacy and leadership buy in could contribute toward intervention to protect the fetus, infant and child from environmental hazards. One group discussed how advocacy can lead a person

to information and safety resources. Some people don't have a lot of support, so advocates can help fill a void or meet a need in a situation.

Leadership buy in was also discussed by one group. The group discussed the importance of "leadership buy in" as this draws attention to the need for interventions.

> I think buy in from leadership, whether it is health care organizations or community, helps get interventions implemented appropriately and more effectively.
>
> The lack of "buy in" from people who make the decisions makes it difficult to address issues and implement interventions.

Focus Group Question 8

The eight focus group question, "What do you see as gaps in policies at the tribal, county or state levels that would provide protection to the infants and children for environmental health risk?" was discussed by four of the five groups. The topics and number of times each theme was mentioned is found in Table 10.

Table 10: Question 8 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Lack of Consistent Laws (ETS)	2	3	0	0	1	6
Lack of Agency Coordination/ Collaboration	0	3	0	0	2	5
Lack of Primary Seatbelt Law	1	3	0	0	0	4

Question eight was asked to evaluate local policies. Focus groups were asked to identify gap that they know of, that would provide protection to infants and children for environmental health risk. This question was addressed among four out of five of the focus groups. The groups did not spend much time discussing this question. Moderator variability was evident and two of the groups had to be redirected because their discussions were not addressing the question. The three most prevalent themes among the groups included a lack of consistent smoking laws, lack of agency coordination and the lack of a primary seatbelt law.

Lack of Consistent Smoking Laws. The most frequently discussed gap in policy was that of inconsistent smoking laws. The theme was discussed in 60% of the groups and was mentioned approximately six times. The groups agree that both governing bodies should have passed the anti-smoking law instituted by the state. Instead, within the local area reservation boundaries, there are two different laws. The tribe has chosen to implement their own anti-smoking law, which is less stringent by allowing smoking in some buildings, and no distance restriction from doorways.

> The thing that comes to mind for me is the lack of togetherness that should have been taken on the public smoking issue. I felt that our tribe did not take a stand to protect the people.

Another individual shared that although the tribe chose not to follow the State's public smoking law, they have come a long ways on taking a stand on minimizing environmental tobacco smoke. The participant goes on to share stories about how the tribe no longer condones smoking indoors at wakes, council chambers and has implemented enclosed designated smoking areas in some of their public buildings.

Lack of Agency Coordination. The lack of agency coordination was a theme discussed as a gap in policy that if addressed could potentially protect infants and children from environmental risk. The theme was discussed in three of five of the groups and mentioned approximately five times. Groups discussed the lack of agency coordination and collaboration as a process that causes confusion for understanding policy. One group discussed how difficult it was to know what the policies are because of the lack of communication and coordination among governing agencies, the tribe, the county and the state. Another group stated that there are differing definitions of whose rights are being protected and whose rights are being violated resulting in decisions that place children at risk.

> I guess my opinion is that things get too political between the tribe, county and state, so nobody works together.

Another disconnect in agency coordination concerns the health care system and social services. Health care providers are mandatory reporters. However, their duty to report is not reciprocated. As a result, health care providers have no recourse to follow up as to whether or not any intervention took place. Another person advocated for the need to have a community health nurse involved in foster care for health purposes such as immunization and diets.

> One legislative issue that did not pass into a law; currently, a foster parent may not have health information for a couple of months and may have to be the person who tracks the information down. . . this lack of coordination places children at risk.

One group commented on how local agencies have found ways to get around policy to collaborate. They discussed how such efforts are protecting children from potential

harmful environmental exposures. One group reviewed local mortality to identify trends and bring awareness to the community to prevent further fetal, infant and child mortality.

Lack of Primary Seatbelt Law. The groups were also fairly consistent about the lack of a primary seatbelt law being a policy gap that if addressed could provide protection to infants and children from environmental risk. The theme was mentioned in 60% of the groups and mentioned four times.

> The fact that Montana does not have a primary seatbelt law despite having been in front of the legislation for the past seven years since I have moved here is ridiculous.
>
> The lack of a primary seatbelt law for children is criminal. I mean it is just negligent on the part of the state…

Another individual discussed how the current seatbelt law is not taken serious by the public because of its "secondary law" status.

Other Pertinent Information. Participants made various comments that were pertinent to the question for their local area. One person made reference to "18 money". This is money each member of the tribe receives once they reach the age of 18. The participant recalls when 18-year-old tribal members were given thousands of dollars and ending up in car wrecks and dropping out of school. However, the implementation of additional policies has seemed to minimize negative outcomes.

Another participant shared her thoughts that policies don't resolve everything and people have to want to change behaviors.

> You can discuss policy but if people don't have the desire to change they are just going to go out behind the barn and do whatever they want--you can't force people to do anything.

Although others agreed, they stated there is still a responsibility to protect the public.

One group discussed whether or not the implementation of updated wellness exams could be placed as part of the requirements for receiving public assistance.

> Our tribe (area of study) requires that all children have updated immunizations before a person can receive public food benefits, which is one of the reasons we have such high immunization rates.

Focus Group Question 9

The ninth focus group question, "Is there an existing group or resource in our area that could be utilized to address/follow/advocate for pediatric environmental health issues? Explain." was discussed by four of the five groups. The topics and number of times each theme was mentioned is found in Table 11.

Table 11: Question 9 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Tribal Council	0	3	0	0	0	3
Tribal Health	1	2	0	0	0	3
FICMR	0	1	0	0	1	2

Question nine was asked in order to identify other groups or resources currently established that might be tapped to assist with pediatric environmental health issues. This question was answered by four out of five of the focus groups. With this question, groups listed entities, but there was little discussion on why they might be good resources to address pediatric environmental health issues. The top three entities that were most

discussed included, tribal council, tribal health, and Fetal Infant Child Mortality Review Team (FICMR).

Tribal Council. Tribal council was discussed as an existing entity in the local area to be utilized to address pediatric environmental health issues. The theme was discussed in one group only. However, there was a broad discussion as to why they thought the tribal council was an important resource. One reason the group was listed was that they approve and implement a majority of the policies for the area. Once an issue is discovered, it has to be brought before council before any changes or interventions are implemented. The correlate of tribal health, the county board of health was also mentioned as a resource.

> The one that we have to go to, and when I say we-I mean tribal health is the tribal council, we are governed by them. That is where we would have to go if we are going to talk policy…
>
> Certainly tribal council, they are the decision makers but they don't make a decision without getting information from another source.
>
> They dictate policy . . . they are usually not the ones in the field but for the most part they are the decision makers on the issues brought before them.

Tribal Health. Tribal health was also listed as an existing resource that could address/follow/advocate for pediatric environmental health issues. This group was thought to be a resource because they have community health nurses that work directly with the population and they deal with a broad range of mortality and morbidity issues. They were also thought to be a resource because they currently have a workable model to address change with heart disease and diabetic patients.

Fetal Infant Child Mortality Review Team (FICMR). The FICMR team was thought to be a good resource to address, follow, and advocate for pediatric environmental health issues because they are a group that combines tribal and county entities. The team has a broad array of professionals that have knowledge about the health of the fetus, infant and child. The team is made up of legal and professional members including doctors, nurses, social workers, child protection team members and hospital personnel. Also, their topic of interest is the fetus, infant and child.

> It is a very active group of people. So that is one team that you could use as an advocacy group because they are focused on children and infant health.

Other Pertinent Information. The groups offered names and discussion points regarding other associations that could be utilized to address/follow/advocate for infants and children. The public health department was also thought to be an existing resource for pediatric environmental health issues. They currently have a program in which nurses do prenatal and postnatal visits to first time moms. The department also has a program that addresses child safety. However, the program is currently focused on motor vehicle safety, but as funding permits they have dealt with subjects such as water and bicycle safety. Another participant discussed how there were a number of coalitions in the area including breast feeding and Boys and Girls Club that could also be resources for pediatric environmental health issues. Finally, the Head Start program was thought to be a resource. The Head Start group touches a vast majority of the reservation population, including parents and children.

Research Question 3: Health Care Providers

The final three questions were directed toward capturing the health care providers understanding of pediatric environmental research and their educational needs. Moderator variability was present with one group not able to answer all of the questions. The question was addressed by four out of five groups.

Focus Group Question 10

The tenth question, "What educational methods would be most helpful to improve health care provider competencies in pediatric environmental health? What topics regarding pediatric environmental health would you like to learn more about?, was discussed in four of the five groups. The topics and number of times each theme was mentioned is found in Table 12.

Table 12: Question 10 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Conferences	3	0	0	0	4	7
Webinars	1	1	0	1	1	4
CEU/Curriculum	2	0	0	1	1	4
Electronics	0	2	0	1	0	4
Chemicals	2	0	0	1	0	3
Effects of Exposure	2	0	0	1	0	3
Substance Abuse	1	0	0	0	0	1

Question 10 was written in two parts. Four of the groups asked the first part of the question but only three of five groups asked the second part. The question was asked in order to determine preferred health care provider educational methods. Also, this question was intended to gather data on pediatric environmental health topics of interest. The top three themes concerning educational methods included conferences, webinar and the opportunity to receive continuing education units. The top three themes captured as topics of interest in pediatric environmental health were, chemicals, substance abuse, and biphenyl A (BPA). Participants listed their preferred methods of educational topics but little rationale was offered on either question.

Conferences. Conferences were the preferred method of education for improving competencies in pediatric environmental health. Conferences were mentioned approximately seven times, in two of the five groups. Local conferences were most preferred but participants understood that this was not common to the area, and travel is most often necessary. Participants also embraced the idea of conferences because they serve as a forum to expand networking and building collaboration. Participants discussed how they would like to see Babies and the Environment (the pediatric environmental health conference offered the morning prior to the focus groups) in the local area with different topics or more information on topics presented.

Webinars. Webinar was the next discussed method of education for improving health care provider competencies in pediatric environmental health. Webinars were mentioned approximately four times, in eighty-percent of the groups. Participants thought

that webinars were the most accessible form of interactive education. With this method less work time is missed.

Continuing Education Units (CEU). Continuing education credits were also discussed as convenient method to enhance competencies in pediatric environmental health. Continuing education credits were discussed approximately four times by three of the groups. Participants thought that this would be a good venue due to the fact that for some licensed health professionals, CEU's were mandatory for maintaining professional licensure, therefore; having pediatric environmental health as a topic toward CEU's would help increase knowledge and competency in this area.

Other Pertinent Information. Other methods that participant felt would be useful in enhancing competencies in pediatric environmental health included topics recorded electronically, either audio, audiovisual or downloadable from a computer in which a person could listen to at their convenience. This method also minimizes time away from work and travel.

Chemicals. Chemicals were the most discussed topic of interest. Chemicals were mentioned three times in two out of five of the groups. Participants felt like they hear about "the big issues, tobacco and alcohol" but they are less knowledgeable about chemicals.

> We all make ourselves have peripheral knowledge or incidental knowledge, but to have a more formalized education would be good.

Effects of Exposure. Participants discussed how they would like to learn more about how environmental exposures affect the developing fetus, infant and child. The effects of exposures were mentioned three times in two of the groups.

Substance Abuse. Finally, participants discussed how they would like to learn more about methamphetamine. Substance abuse was mentioned one time and by one of the groups.

> "It is somewhat known that children exposed to substance abuse in-utero have behavioral problems, but I want to know what data is out there, what is known."

Other Pertinent Information. Participants also mentioned other topics of interest in regards to pediatric environmental health. One person commented on how they would like to learn more on advocacy, how to go about it, how to reach key people to address an issue. Another person discussed how they would like to hear about practice models that have been tried in the area of pediatric environmental health. "How did the model help, or why did a model not work".

Focus Group Question 11

The eleventh focus group question, "Earlier we discussed community-based participatory research (CBPR). How might a busy health care provider be involved with CBPR?" was discussed in four of the give groups. The topics and number of times each theme was mentioned is found in Table 13.

Table 13: Question 11 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Provide Data	2	1	0	1	4	8
Participate in Research Process	0	0	0	2	2	4
Identify Problems/Needs	0	1	0	0	1	2

The focus groups were asked to consider how health care providers would like to be more involved in research. Suggestions included providing data to the researcher, participating in the research process and assisting with identifying problems and needs in the community.

Provide Data. The participants discussed how they are in a position to provide and collect data. The "provide data" theme was discussed in four out of five of the groups and mentioned eight times. Participants discussed how they are in positions that allow them to have access to data that might be useful to the researcher. Also depending on the topic, health care providers can also be utilized to collect data. One person suggested that data collection, if not too involved, could be incorporated into a clinical visit. Another example of data collection was that of doing surveys in the community for the researcher, since they have an established access and trust relationship with the community.

Participate in the Research Process. Participants also discussed how health care providers could be in involved in CBPR by being active participants in the research process. The act of participating in the research process was discussed in two of the

groups and mentioned approximately four times. Groups discussed an active role in participation by being the community link or identifying key players needed to assist in the research process. One also described how they could serve a liaison between the primary investigator and the community. Another participant discussed how they are involved in a research study and how such involvement facilitates professional development.

Identify Problems/Needs. Finally, the third most common theme identified by participants included assisting in identifying needs and problems in a community. Identifying problems/needs was discussed in two of the groups and mentioned approximately twice. One person commented on the how CBPR allows the community to decide what they would like to know more about, therefore one participant discussed how health care providers could fulfill this process because they are aware of issues needing to be addressed in their specific community.

Focus Group Question 12

Focus group question twelve, “Today we focused on health care providers perception’s of pediatric environmental health. Which individuals or agencies not here today, could provide information that would enhance our knowledge of pediatric environmental health on this Northwest Reservation/County?” was discussed by four of the five groups. The topics and number of times each theme was mentioned is found in Table 14.

Table 14: Question 12 Topics and Number of Times Topic Mentioned

Topic/Theme	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Law Enforcement	2	0	0	0	2	4
Tribal Environmental Health	1	2	0	4	0	3
PCP	0	2	0	1	0	3

The center of data collection among the focus groups consisted primarily of local practicing health care providers. Therefore, the final question was presented to the groups in order to determine what other individuals or agencies needed to be included in order to enhance our knowledge of pediatric environmental health issues in the local area. The question was addressed by four of the focus groups. Although there was minimal elaboration on the themes discussed; the top three included law enforcement, tribal environmental health, and primary care providers.

Law Enforcement. Law enforcement was discussed among focus groups that could help enhance knowledge of pediatric environmental health issues in the local area. Law enforcement was mentioned by two of the groups and discussed approximately four times. One reason groups suggested law enforcement was because they provide training in methamphetamines and have knowledge about substance abuse in the local area. Another group discussed how law enforcement are in the homes and therefore have the opportunity to see environmental exposures that may have the potential to be harmful to infants and children.

Tribal Environmental Health. The tribal environmental health was also mentioned as an entity in which knowledge of pediatric environmental health could be enhanced. This entity was discussed in three of the focus groups and mentioned approximately three times. Tribal environmental health was thought to be a resource because they do training on handling hazardous materials as well as treatment of exposure to hazardous material. They are also a community link to policy makers within the tribe.

Primary Care Providers. The groups discussed how primary care providers were a good resource for enhancing competencies in pediatric environmental health. The theme of primary care provider was discussed in two of the groups and mentioned approximately three times. Primary care providers were thought to be key resources because they evaluate and treat children. Due to the lack of pediatricians in the area, the care of children falls upon the general practitioner, whether it is medical doctors, nurse practitioners or physicians assistants.

Other Pertinent Information. The groups had many ideas of what agencies could enhance knowledge of pediatric environmental health including school officials, child care attendants and head start due to their daily interaction with parents and children. One participant suggested “environmental agencies” should provide information to enhance knowledge in the area of pediatric environmental health. They could provide useful information on the scientific aspects on topics such as pollution.

Conclusion

The introduction of this chapter identified the means of data collection via focus groups made up of local health care providers. Focus groups were led by trained moderators who guided participants to discuss their perceptions on topics of pediatric environmental health. Table 2 introduced the major themes identified through the twelve-question instrument (Appendix A) used to guide the focus group discussions. Demographic data identified the characteristics of participating health care providers in relation to their expertise and link to the community of study. Although moderate variability existed, four of the five groups were able to complete all twelve questions. Inter-rater reliability related to the major themes was established by having the principal investigator of the project determine the primary themes of three questions.

The groups began by discussing the health care providers' perception regarding environmental hazards that could affect fetal, infant and child morbidity and mortality. Participants seemed to lean toward behavioral aspects of the environment and less (although present) toward the physical environment. The discussions then lead into environmental health issues that could impact the fetus, infant and child. The groups discussed the most common environmental exposures significant to the local area. Providers discussed avenues of their personal practice involvement as well as identify interventions to potential harmful exposures. Barriers and gaps were discussed as far as addressing pediatric environmental health in the area. Participants incorporated "priority" as a major theme into many aspects toward their discussion of environmental health issues. Finally, groups discussed topics of expanding their knowledge on the topic

including self education, participation in CBPR and potential other potential local networking agencies or individuals. Participants found the topic of pediatric environmental health as a favorable topic in which they would like to learn more. Participants showed interest in the discussion and willingly provided their experiential knowledge to each topic.

The focus groups amassed a vast array of information concerning local issues related to pediatric environmental health. The next chapter will discuss and summarize the qualitative data obtained through the focus group discussions.

CHAPTER 5

DISCUSSION

Summary

Health disparities continue to be a problem for children of AI/AN descent. Mortality rates are higher than that of the dominant culture. Asthma has been identified as a leading cause of disease in children in this population. Environmental exposures such as tobacco smoke and lead have been linked to poor health outcomes in the fetus, infant and child. Health care providers are identified as key players in the prevention of mortality and morbidity related to hazardous environmental exposures. However, 85% of health care providers attending a pediatric environmental health conference indicated they had never received any formal training related to environmental health topics, including recognizing, managing, treating and effectively educating patients on environmental exposures.

The purpose of this study was first, to work with a community-academic partnership to sponsor an environmental health continuing education event for health care providers working with the tribal and non-tribal local population; second, to utilize a community-based participatory research approach to tap local health care provider expertise and identify potential environmental exposures on one Northwest Indian reservation and the principal county within the reservation; and finally, to gather information on future environmental health education needs of local health care providers.

Data were collected via moderator-led focus groups comprised of local health care providers. Participants were asked to discuss 12 questions (Appendix A) related to local pediatric environmental health issues. Focus group sessions were recorded and then transcribed by a professional transcriptionist. The data were analyzed using content analysis and the most common themes were identified. Other pertinent themes deemed significant to the topic or the area were also identified. The study was framed using the theoretical framework of Community Based Participatory Research (Viswanathan 2004); the goal was to first build community links that could help connect the researcher with local health care providers and then collect data via local expertise and perception from local health care providers. The Translational Environmental Research in Rural Areas Framework (TERRA) (Butterfield & Postma 2009) was adapted by substituting environmental health risk and risk perception of rural families for that of health care providers working with families facing challenges of poverty. Reviews of the main conclusions of the data analysis are provided for each of the following research questions.

Conclusions

Research Question 1: Health Care Provider Perceptions

The five focus groups generated a vast amount of information related to health care provider perceptions of pediatric environmental health issues in the community. Many of the participants perceived environmental health as something that has the potential to affect the well being of an individual whether it is related to their social or physical environment. Participants were the most sure of their perceptions regarding

SIDS as the leading cause of death of infants and children in the community. Even though community/public health and hospital resources are geared toward eliminating this condition, SIDS continues to be a problematic issue for the community. Parent/caregiver education was identified as a primary need. Rather than discussing morbidity issues, most of the groups tackled problems and solutions including the need for more maternal education and resources to serve the population. The expectation was that they would discuss their experiences with illnesses such as asthma, cancer or other diseases linked to environmental exposures. Substance abuse was discussed or at least mentioned among all groups in terms of its relation to pediatric environmental health. The discussion of morbidity seemed to shape the remainder of the focus group discussions toward behavioral rather than toxin links with environmental health and illness.

Focus Group Question1. "When I hear the phrase environmental health I think of . . ." Participants discussed environmental health in terms of the community. The community was evaluated in terms of geography, culture, personal values and the physical areas of everyday human function, such as home, school and work environments. As health care providers, it was important for participants to look at the make-up of their community because that was the basis for defining environmental health and how it affects them locally. Participants also discussed safety as a prominent theme. From the community /public health nurse point of view, attention to safety is a significant part of their job. They evaluate an environment in terms of risk and possible measures of risk reduction. For instance, if a child does not have a car seat then it is the role of that

community/public health nurse to act in order to implement environmental risk reduction. Lastly, the groups listed toxins as a prominent theme. Although participants mentioned toxins, their responses were vague thereby revealing early awareness of conference topics and the need for more knowledge related to specific toxins.

Focus Group Question 2. "As a health care provider, what do you perceive as the leading causes of infant/child mortality in our area?" The fact that participants overwhelming discussed SIDS as the leading cause of infant/child mortality was in agreement with regional and national data linking this condition to the most common cause of infant/child mortality among AI/AN ([USDHHS], IHS, 2008; Kvign et al., 2008). Participants seemed unanimous in their ability to attribute primary mortality to SIDS. Many of the participants voiced experience in dealing with infant mortality either microscopically, in an acute setting dealing with a SIDS case or macroscopically, as a member serving on the local Fetal Infant Child Mortality Review (FICMR) team. The need for more maternal/family education, a primary topic among the groups is also reflected in the scientific literature. Education deficits are linked to lower maternal age, teen pregnancy and substance abuse issues. Groups identified the need for more maternal/family education as a SIDS prevention strategy. This concern for family/maternal education is also supported in the literature (Castor et al., 2006; Blabey & Gessner, 2008). Findings in the literature also align with group discussion related to small for gestational age, low birth weight, improper infant bedding and environmental tobacco smoke, contributing to local area SIDS cases (Alexander et al., 2007; Baldwin et al, 2008; Castor et al., 2006; Gaudino, 2008). Health care providers established the need

for more resources and maternal/family education to promote healthy outcomes and prevent infant/child death.

The participant's wider definition of environmental health was captured when they discussed motor vehicle accidents as a leading cause of death. The repetition of this topic suggested that this issue is a priority in this local community. Perhaps one could assume that due to the local reservation's rural distance characteristics and lack of public transportation, motor vehicles are essential for providing basic needs. Therefore, this issue is perceived as a primary environmental risk. Participants acknowledged the importance of risk reduction and the need for continuous maternal/family education and resources focused on this issue. The value of focus groups and community-based participatory research is the opportunity to capture themes of major concern to the local community. Although an important public health issue, "motor vehicle accidents" is not found in the environmental toxin literature but this focus group theme as well as the discussion of SIDS, points out the challenge and danger of attempting to separate preventable toxins from preventable behaviors.

Focus Group Question 3. "As a health care provider, what do you perceive as the leading causes of infant/child morbidity in our area?" Participants discussed three themes related to morbidity including lack of resources, weight management and safety. In all groups, participants wanted to discuss contributing factors. Although weight was discussed in terms of obesity, the literature indicated that some toxins are linked to disruption of the endocrine system. Associated with BPA, the chemical product used to harden plastic disrupts the endocrine system and affects neurologic and behavioral early

life development (Vandenberg et al., 2010). BPA is associated with canned and plastic wrapped foods (Erler & Novak, 2010). It can be assumed that such foods are those that are most accessible either because of convenience or socioeconomic factors (commodities or food bank supplies). Although BPA has not been linked to obesity, the direction of the focus group discussions demonstrated the HCPs interest in conditions currently at the forefront of HCP practice and the inability to name conditions (e.g. asthma; neurobehavioral problems) that are also prevalent in the community that could be linked to exposure to toxins.

Lack of resources was discussed in terms of risk and risk reduction measures. Participants were concerned about the sustainability of prevention programs. Although the groups acknowledged the importance of pediatric environmental health issues, they also recognized that prevention may hold less priority compared to more acute and immediate practice. This point highlighted the resource challenge. Without resources health care providers cannot receive training, education cannot reach the public, and prevention measures cannot be implemented. Lack of resources reflects the inequities of a rural ethnic community as guided by the TERRA framework.

Safety was also discussed as another factor related to excess morbidity. The topic was raised in relation to parental/caregiver choices and behaviors. Participants believed that poor choices such as substance abuse, environmental tobacco smoke were determinants of health and well being of children. When exposed in-utero children can suffer as a result of fetal alcohol syndrome (FAS), Attention deficit hyperactivity disorder

(ADHD) or other behavioral problems. Again, the toxin plus behavior connection was identified.

Research Question 2: Environmental Health Issues

Upon discussion of environmental health issues, valuable insights into the community were provided. Most groups continued to discuss substance abuse (smoking, drugs and alcohol) as a primary issue; however, they also identified community assets including services and resources. Groups recognized that their community has valuable resources and also agreed that they could be more influential and reach more of the population as they continue to find ways to improve communication. Participants were very sensitive to the cultures of their community. They not only discussed culture in terms of ethnicity, but they also acknowledged cultures of age and lifestyles. Individuals seemed to frame the approach to their work based on the culture of the patient. Education was a main them throughout the discussion. Participants discussed how the subject of environmental health affects many entities. There are a number of venues in which pediatric environmental health can be addressed, which is likely the reason participants frequently focused on the need for education of the community, including health care providers. The discussions that focused around education reflected that health care providers are addressing pediatric environmental health issues in their practice. Perhaps, because they are not using the terminology “pediatric environmental health” they did not identify themselves as practicing in such capacity.

Focus Group Question 4. "What possible environmental health issues could impact the health of the fetus, infant, or child? Of this list, which are the top three?" Participants chose drugs/alcohol, tobacco smoke and methymercury as the most important environmental health issues in the local area. Drugs and alcohol represent a historical social issue that has plagued AI/AN communities. Tobacco smoke is said to have always been a part of the AI/AN culture. Smoking tobacco was a gesture of friendly relations and was used ceremonially. However in later years the residue from tobacco smoke has come to be known as an environmental toxin that has the potential to impede the healthy development of AI/AN children. Finally, participants were intrigued to learn about methymercury. After developing an understanding of exposures and potential problems related to exposure, participants seemed to have a heightened awareness that methylmercury was a potential exposure. In the discussion of pesticides, it was obvious that although providers were aware of the vast amount of agriculture that takes place in the area, they did not have a deep understanding of the potential harm over exposure that could have an impact on a developing fetus, infant and child.

Focus Group Question 5. "In what ways are health care providers involved with pediatric environmental health issues in our area? How can a health care provider's involvement be enhanced?" Participants revealed that they found themselves most involved in pediatric environmental issues via education, prevention and resources. "The potential for an agent to induce a health problem is considered an environmental health risk" (Butterfield & Postma, 2009). The priority issues being addressed, reflected throughout the focus groups discussions, included prenatal care and SIDS prevention

with the greatest risks identified as tobacco smoke, methylmercury, substance abuse, and motor vehicle accidents. Educating the community and self in PEH was an important concept among the groups. Prenatal programs provide education to expectant moms on topics to improve health outcomes for infants. The programs also incorporate SIDS prevention and tobacco smoke exposure. The prenatal population reached by the programs often reflect the inequities identified by Butterfield and Postma (2009), including rural, lower socioeconomic status and member of an ethnic minority. Consistent, continuous, and novel health promotion efforts targeting this group are needed. Tobacco smoke is a primary exposure in the local population. Participants discussed how the community had a vast smoking population and how they have experienced working with individuals highly addicted. Participants have identified efforts to reach school age children and pregnant women as a means of prevention. Substance abuse was another priority issue. The focus of concern seemed to be on the effects to infants and children. Health care providers represent one solution to a problem that requires a multi-faceted approach. Health care providers benefit from continuing education on priority local community issues, and prevention/intervention efforts. For instance, methylmercury was identified as a priority issue. Most inquiries about methylmercury came from participants self proclamation that this was an issue that they learned about during the Babies and the Environment conference. Their interest in methylmercury was related to the potential exposure and the impact the addition of this knowledge would have on prevention efforts in their practice. Finally, motor vehicle

safety was a priority issue of concern to local health care providers. Motor vehicle accidents were also a priority theme among the groups.

Focus Group Question 6. "What are the barriers to enhancing/adding environmental health to a health care provider's practice?" The priority of acuity and emergent issues was the most prominent theme discussed as a barrier to implementing pediatric environmental health into a health care providers practice. Urgent client issues compel health care providers to give priority to reactive rather than preventative approaches. Secondary and tertiary medicine is the primary means of health care; as a result health care providers may miss opportunities to assess the environmental health issues that could impact infants and children. Exposure to tobacco smoke was the most screened environmental health issue likely because it is the most obvious and prevalent environmental health issue linked to diseases such as cancer, respiratory problems, and SIDS. Financial resources were also thought to be a barrier to incorporating PEH into practice. Finances are most commonly distributed based on demand and need. One can assume that due to the fact that it is difficult to link a specific exposure to a specific disease (Briggs, 1999), pediatric environmental health is not easily measured; an exposure is difficult to detect. In addition, toxic exposures can be insidious and prolonged which gives the appearance of a non-existent problem that results in little priority given in terms of time, effort and resources. The concept prioritizing tangible risks (most understood/seen) over intangible (least understood/invisible) is reflective of the environmental health mental model of risk perception (Butterfield & Postma, 2009).

Focus Group Question 7. "What interventions are needed to protect the fetus, infant, or child from environmental hazards?" Interventions identified among the discussion included education, resources and laws. These three components of interventions reflected a ripple effect. Each intervention strengthened the next. First, a message is distributed through an education effort. However, the message cannot move forward without a vehicle. Resources act as the vehicle utilized to deliver the message. Finally, the enactment or enforcement of laws strengthens the message. Laws keep people mindful of potential harms that could result from an exposure. Participants' recognition of the importance of education is reflected in the literature (Rogers, 2004). Uninformed, first-time or young mothers may need more resources such as early prevention and education interventions to improve healthy birth outcomes. Most commonly poor birth outcomes occur in those of young age, least educated, ethnic minority and from a lower socio-economic group. Related resources help even the playing field for those who face such challenges. Laws and policies protect those who cannot protect themselves. Fiscal resources funneled toward PEH intervention such as education will improve environmental risk reduction. Action taken to minimize risk is reflective of environmental risk reduction interventions addressed in TERRA framework. Prevention and education are not only acts the will improve birth outcomes but enhance risk reduction in other areas of the community (Butterfield & Postma, 2009).

Focus Group Question 8. "What do you see as gaps in policies at the tribal, county or state levels that would provide protection to the infants and children for environmental health risk?" The focus group transcripts indicated that participants had

firm ideas of what they see as gaps in policy to provide protection to the fetus, infants and children. Many participants voiced a concern for the dearth of protective policies. A lack of consistency in laws was discussed mostly in part in regard to the anti-public smoking law initiated by the state. However, participants felt that the tribal community was unprotected as the tribal government opted not to follow suit. Therefore, non-smoking tribal members find second-hand smoke offensive while in the vicinity of a tribal establishment. The health care sector does not feel supported in their anti-smoking tobacco efforts. Along these same lines, participants discussed a lack of agency coordination and collaboration. The interest of self government is more important than to work together on local issues. Tribal sovereignty is important to the local tribe. They pride themselves in self management of the functions of their historical territory. However, in this situation there are three governing agencies located within tribal/county boundaries: the tribe, the county and the state. Each governing agency desires for their voice and ideas to be heard and implemented. When a collaborative agreement cannot be determined each governing agency implements a separate policy. As a result members of the community look for ways to function while at the same time respecting all governing bodies in which they operate.

Finally, the lack of a primary seatbelt law was strongly voiced among participants. The geographic area of the reservation/county is rural. The area is made up of several communities. There is little opportunity to live within walking distance to employment, schools and shopping. As a result motor vehicle is a primary part of everyday function. Safe driving practices is a concern in the community. As a result,

health care providers identified this issue as continually needing attention because infant/child mortality/morbidity related to motor vehicle accidents is preventable. Since the discussion among the focus groups, the state has implemented a primary seat belt law. Children under the age of six-years or 60 pounds must be restrained in a moving vehicle with restraints appropriate for the child's weight and height (http://data.opi.mt.gov/bills/mca61/9/61-9-420.htm).

Focus Group Question 9. "Is there an existing group or resource in our area that could be utilized to address/follow/advocate for pediatric environmental health issues? Explain." Focus groups named tribal council, tribal health and FICMR as the existing groups or resources that could be used to address/follow/advocate for pediatric environmental health issues. The tribe manages many programs, which are in operation across the reservation, including the health care system(s) in which many of the focus group members are employed. The reservation covers much of the county. As a result, many of the focus group participants are key players in implementing policy. Therefore, if there is a health concern in the community, the tribal council group would decide how many and which resources would be allocated. Although the process may take some time before the issue is considered, this elected group represents the decision making body for the tribe. Tribal health was the other agency listed as a group/resource to address/follow/advocate for PEH issues. Tribal health is a health care system managed by the tribal council. They are available in almost all of the communities with teams available to go out into the community. They are a highly functional and well informed resource adept at linking resources offered by the tribe and county. Tribal health is also in

place to identify and follow health issues that need to be addressed, and they can advocate for and educate the public. Lastly, this group has successfully collaborated/coordinated efforts with the county health department allowing them to confront issues at multiple levels. The last group identified was the FICMR team. This team is a group of professionals from multiple sources of the community. They review each infant and child death, evaluating the circumstances and causes. As a result they are able to identify trends and advocate for interventions.

Research Question 3: Health Care Providers

Health care providers were interested in discussing the topic of environmental health. They felt this focus was an important area that could use more attention. However, at this point in the discussion, responses became more specific with little dialogue. One might assume that participants were likely tiring after five hours of lecture and two hours of focus group discussion. Participants surprisingly did not discuss their rural environment and travel as a barrier to education. Technology is readily available to most practicing providers in the area. Health care providers were interested in learning more about maternal/parental substance abuse. One can assume that the heightened attention to the problem or topic may be related to the fact that health care providers deal with the issue on a regular basis.

Focus Group Question 10. "What education methods would be most helpful to improve health care provider competencies in pediatric environmental health? What topics regarding pediatric environmental health would you like to learn more about?" The

educational methods participants discussed included options that kept them close to their work environments and that were convenient to access including webinars, CEU curriculum and material accessible via electronics (CD, DVD, computer downloads). Conferences were preferred but are more costly and travel is most often required. Being from a rural location, conferences can take a person from their worksite for nearly a week. However they were interested in interactive learning experiences. Conferences also serve as a forum to build networks with other health care experts.

The participants wanted to learn more about the effects of exposure to methamphetamine. In the local area their issues related to drug abuse, including methamphetamine and prescription drugs. More than ever, prescription drugs have become a major issue on the reservation. There are many resources, including health care, mental health and law enforcement, focused on an effort to curb the problem. In the meantime, health care providers deal with situations regularly in which they have to address problems of substance abuse. Secondly, participants wanted to learn more about chemicals. This study confirmed findings in the literature; local health care providers feel ill equipped to recognize, assess, educate and intervene on pediatric environmental health issues and most lack formal training or continuing education in this area.

Focus Group Question 11. "Earlier we discussed community-based participatory research (CBPR). How might a busy health care provider be involved with CBPR on the reservation?" The discussion on CBPR attracted interest among the participants. Many of the respondents vocalized their desire to participate in research. Their ideas toward a means of participation included providing data, participating in the

research process, and assisting in identifying needs. In keeping with the CBPR literature, the focus group process paralleled the approach of this method of research. Group participants recognized that as health care providers they have the potential to play important and valuable roles in research opportunities that affect their community. However, they seemed to be most available in the confines of their health care position. A health care provider can only effectively function when they have an understanding of their community, including patient needs/issues, and resources. The perception was that members of the focus groups felt they were the most informed about their community to identify issues that might benefit for research. The approach of CBPR values the role of the community in the research process. The focus groups brought community member (health care provider) insights and expertise to the forefront to help identify local issues. Through lived experience participants revealed issues most familiar to them that they attributed to be aspects of pediatric environmental health. They identified themselves as responding to priority issues by practicing prevention by way of education and by either acting as a resource or referring or utilizing other available community resources.

Focus Group Question 12. "Today we focused on health care provider perception's of pediatric environmental health. Which individuals or agencies not here today, could provide information that would enhance our knowledge of pediatric environmental health on the reservation/county?" When discussing other individuals and agencies in the area that could possibly enhance knowledge of pediatric environmental health, participants chose law enforcement, tribal environmental health, primary care providers and school officials. The emphasis on the behavioral environment during

discussion likely influenced participant's choice of law enforcement. In their respective roles, they go out into the community, most often in a response to crisis in which they are trained to analyze and evaluate situations. The enforcement in the local area is representative in the forms of tribal, county and city jurisdiction. Their knowledge about the community and the substance abuse issues, as well as their availability in the communities point to the qualities that made them a choice. The other entity identified by focus groups was the tribal environmental health. This entity is knowledgeable about local environmental policy as well as geographical land base. They can be tapped for information about potential local environmental hazards that need to be addressed in order to protect the fetus, infant and child. They are a link to the policymakers of the tribe. However, the manpower is very small, and they have a large scope in which they are responsible, so perhaps their county counterpart may also be sought as a contributing source.

Primary health care providers were another group identified by participants to enhance knowledge of pediatric environmental health. They are a first line of health care access and a group that can diagnose disease and potentially identify trends. They have the ability to assess, evaluate, intervene and educate on problems that exist. Finally school officials were named as a group to enhance knowledge of pediatric environmental health issues. It is likely participants valued the input of the schools because they work with a large number of the population including children and their caregivers. There significant roles in education allow them to have insight on neurobehavioral development issues and trends.

The categories of other pertinent information included items that were not mentioned as the top three topics in the content analysis. However, they were discussed because they reflected significant importance to the local community. Topics were discussed under “other pertinent information” either because they were significant to the community of study; or because the theme became a subject important to a group based on in-depth discussion; or the theme was an environmental health issue of local concern. Also significant in “other pertinent themes” a theme may have only been mentioned once or not as often as the top three, but the participant’s acknowledgement of the topic provided informative insights important to pediatric environmental health. Some examples of pertinent information related to “significance of the community” included: culture, mobile population, transportation and 18 money. Themes under pertinent information related to “importance among participants” included immunization, keeping a high rate of immunized children and implementing policies to support such efforts, advocacy and leadership buy-in. Lastly, those other pertinent themes that addressed an “environmental health concern” included a discussion on the ecosystem, water and air quality and the recognition of pesticides and the active agricultural community in the area.

The TERRA framework’s “environmental health mental modes” discuss how risk is perceived through thoughts and feelings which then ultimately lead to conclusions of how a risk might have an impact. The authors further speculate that, “personalized understanding of risk is developed via a cognitive analytical system and an intuitive experiential system (p.112).” Therefore experience impacts response to an issue. The

framework also considers tangible versus intangible environmental health risks. Tangible risks are those most readily visible. Intangible environmental health risks are less frequently observed and can be silent and unseen. Related to this concept, focus groups for this study concentrated on the most tangible environmental health risks they experienced most in their community. The tangible risks for this study included the more behavioral aspects such as substance abuse (tobacco smoke, drugs and alcohol), motor vehicle safety, SIDS, education and resources. The intangible topics included such topics as methylmercury, indoor/outdoor air quality (carbon monoxide, forest fire smoke), water quality and pesticides. It is possible that local health care providers have not given priority to intangible exposures because these issues can be unseen and unheard or perhaps the issue is given less priority because of the difficulty in controlling exposure to the risk.

Focus groups can elicit a wide range of information. Moderators play an important role by keeping participants focused on the question. Many health care providers are passionate about the health of their community. They would like to address every possible issue they have experienced within their community. They desire to advocate and be a voice for the population and especially infants and children. However, it would be impossible to discuss random topics and expect to accumulate data on the topic of focus. Therefore, a moderator's ability to lead a group and to keep the focus of discussion on the subject at hand is vital to collection of pertinent data.

The introductory focus group question was useful because it allowed the initial insight of the participant perceptions. However, the questions that are most valuable to

the study should be asked first. The order of the first few questions has the potential of dictating the remainder of the discussion. In this study, behavioral aspects were immediately woven into the discussion based on participant responses related to infant mortality and morbidity. Responses surrounding other questions briefly entailed toxins, but participants seemed to be more comfortable discussing social environmental issues.

Focus groups provide rich information about the health and function of the community. This process serves as a means of self-reflection so members of the community can discuss and begin to decide on priority interventions. However, because focus group members generously discuss their experiences, fewer questions with less overlap may have given participants more opportunity for an in depth discussion. In addition to less overlap, fewer questions might have provided more opportunity for the moderator to encourage elaboration on crucial points. In many instances participants would provide a response with no explanation as to why their response supported the topic of pediatric environmental health.

Time is also a significant factor for consideration. The dynamic of time was an influence on the moderator's capacity to clarify responses. Since there were twelve questions, the moderator had only ten minutes to gather responses from eight individuals. Time likely also attributed to the minimal discussion in terms of participants tiring after five hours of conference lecture followed by two hours of discussion. The literature supports a focus group time frame of 1.5-2.0 hours. A planned follow-up session by the research team will be helpful in providing further insight and clarifying responses that had little or no elaboration. In the next phase of this study, meanings could be discovered

rather than assumed and interventions to decrease potential fetus, infant and child exposures can be explored.

Recommendations

The use of focus groups can generate an immense amount of data in a short amount of time. Insight gathered from community partners and groups provides a valuable opportunity to explore environmental health issues. One recommendation is for the research team to return to the community with the primary themes and gather input for confirmation and translation. First the primary themes should be presented to the EHAC, comprised of members of the community. EHAC is positioned to provide feedback via their lived experience and cultural connections to the community. EHAC members also should be asked to identify any information that might be sensitive or have the capacity to depict the community in a negative way. Adding to the EHAC input, select focus group members should be regrouped using the expert elicitation method. Select health care providers can provide clarity to the concepts which lack detail that could be important to this study and future interventions. Finally, the tribal elders are a revered group of people respected for their lived experience and knowledge of tribal history and ways of life on the reservation. Providing elders an opportunity to hear the initial findings and offer contribution in tribal “ways of knowing” (Viswanathan 2004) will strongly enhance the voice of this community and culture as well as help build and maintain trust for further relationships and research.

Additional research to evaluate the processes of confirmation and translation should be evaluated for best practices and shortfalls. Some processes related to this study

would benefit from additional evaluation. One recommended change would be to better prepare note takers. Since the focus groups were audio-recorded only, body language could not be evaluated because note takers were not trained to implement the concept into their notes. Moderators effectiveness might have been improved through training using a simulated practice run of the process, Lastly, if this process is utilized by other tribes or communities, the questions should be reordered, with discussion of morbidity and mortality occurring last, therefore leaving more time to focus on environmental exposures/toxins and health care provider educational needs at the beginning of the session.

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APPENDICES

APPENDIX A

PEDIATRIC ENVIRONMENTAL HEALTH CONFERENCE

FOCUS GROUP QUESTIONS

01/29/10

Introduction Question (go around the circle for responses-ask for "one word" or "phrase")

1. When I hear the phrase "environmental health" I think of….

Infant Mortality (death) and Morbidity (illness, disease, or symptom)

2. As a health care provider on this Reservation/ County, what do you perceive as the leading causes of infant/child mortality in our area?

3. As a health care provider on this Reservation /County what do you perceive as the leading causes of infant/child morbidity in our area?

Environmental Health Issues

4. What possible environmental health issues on this Reservation /County could impact the health of the fetus, infant, or child? Of this list, which are the top three issues?

5. In what ways are health care providers involved with pediatric environmental health issues in our area (reservation and county)? How can a health care provider's involvement be enhanced?

6. What are the barriers to enhancing/adding environmental health to a health care provider's practice?

7. What interventions are needed to protect the fetus, infant, or child from environmental hazards?

8. What do you see as gaps in policies at the tribal, county or state levels that would provide protection to infants and children from environmental health risks?

9. Is there an existing group or resource in our area that could be utilized to address/follow/advocate for pediatric environmental health issues? Explain.

Health Care Providers

10. What educational methods would be most helpful to improve health care provider competencies in pediatric environmental health? What topics regarding pediatric environmental health would you like to learn more about?

11. Earlier we discussed community-based participatory research (CBPR). How might a busy health care provider be involved with CBPR on the reservation?

12. Today we focused on health care providers perception's of pediatric environmental health. Which individuals or agencies not here today, could provide information that would enhance our knowledge of pediatric environmental health on the Flathead Reservation/Lake County?

APPENDIX B

MONTANA STATE UNIVERSITY AND SALISH KOOTEANI COLLEGE

INFORMED CONSENT FORM

Title of Research

Perceptions of healthcare providers of environmental health and infant mortality among American Indians.

Purpose of this research

The purpose of this research is to identify perceptions of health care provider regarding potential environmental exposures in their area of practice and how it may be related to infant mortality among American Indians. American Indians continue to have a disproportionately higher infant mortality rate than that of whites. The most identified causes of death include Sudden Infant Death Syndrome (SIDS), congenital anomalies and prematurity. Health care providers are in a unique position to identify potential environmental hazards and help develop interventions for potential environmental causes of infant death.

As a participant you will participate in a research study that will help identify perceptions of health care providers of your area regarding potential environmental hazards as it may relate to infant mortality among American Indians of your area. You will attend a six hour Pediatric Environmental Health Conference to take place at a local conference center in your area. While in attendance of the conference you will be asked to do a pre and post test on pediatric environmental health. Following the conference you will participate in a two hour focus group discussion in which you will provide input on this topic based on you experience working with the population of your area. The conference will take place in January 2010.

Compensation

Participants will be compensated for their time. Ten continuing education credits will be accredited for your attendance of the conference. You will be awarded a $200.00 honorarium for your participation in the focus group and the knowledge and experience of information you provide during the focus group discussions. Compensation will be provided by the Community/Public health care Provider Initiative.

Procedures

Participants will register for the conference on our website at, http://.www.evenbrite .com. Print this consent form and return to me when you attend the conference.

Risks and/or Discomforts

There are no known risks for participations in this research. It will require approximately 8 hours of your time.

Benefits

Participants will be provided presentations by professionals of pediatric environmental health. You will be given a packet of informational material. As mentioned above you will receive continuing education credit and $200 honorarium.

Confidentiality

Participant's confidentiality will be strictly maintained. Focus groups will be audio recorded only. Participants will be de-identified during data analysis. No individual responses will be identified during focus group discussions. Transcription and data analysis from the focus group will analyze content only and not individual responses. Participant will be assigned a random number for payment purposes only.

Consent to withdraw

Participants can withdraw at anytime during the study. However, since participants will not be identified during audio recording. Therefore, withdrawing after the focus group may be challenging but every effort to remove your statements prior to data analysis will be elicited. You are under no obligation to participate. You may attend the conference without participating in the focus group discussion.

Your signature certifies that you agree to participate in all aspects of the study, including the conference, pre and post test, focus group discussion and audio recording of the focus group. You understand that the input you provide will be utilized in data analysis, which will not identify individuals or individual comments, but be part of a group analysis of themes and patterns identified from the focus group. You understand that you will be provided 10 continuing education credits and a $200.00 honorarium.

Signature of Participant

_____ _____

Signature of Research Participant Date

_____

Print Name

Name and Telephone Number of Investigator

Milissa Grandchamp RN, BSN, Nursing Graduate Student 406-450-1356

Sandra Kuntz, PhD, PHCNS-BC 406-243-2551

13.

APPENDIX C

FOCUS GROUP MODERATOR PROTOCOL

(Developed by Milissa Grandchamp)
01/29/10

Thank you for agreeing to be a moderator for the *Babies and the Environment* focus group session. As a moderator, your role is pivotal to engaging local health care providers in a discussion to better understand perceptions, educational needs, and priority pediatric environmental health issues on the Flathead Reservation and Lake County. Focus groups are a data collection technique that capitalizes on the interaction within a group to elicit rich experiential data. As the moderator, you will be conducting a semi-formal interview with eight individuals utilizing a given set of questions. The interview will be audio recorded using an MP3 player. In addition, you will have an assistant assigned to your group to take written notes. You will guide the group discussion by asking the questions and keeping the discussion on track. You should allow approximately 10 minutes for each question and involve all participants. We have 90 minutes to complete the entire focus group process. The majority of this time should be spent discussing responses to the questions. However, time will be needed for introductions but try to take no more than 5-7 minutes for this process.

1. Welcome

Put the eight participants assigned to your group at ease by asking everyone to take a seat at the table. Your assistant will guide everyone to sign-in (begin the sign-in to the moderators left) and will collect the *Participant Consent* forms prior to beginning the session. Avoid answering questions at the beginning of the session to prevent bias and preempting the discussion. It is the moderator's role to encourage all participants to respond to each question.

Good afternoon. Thanks for attending the conference today and joining this discussion about pediatric environmental health issues.

My name is_____and I work for _____. This is (introduce your assistant)_____who is with_____and will be taking notes during our session.

As you can see, we are also recording this session so we can capture the details of our discussion. Please be advised that no individual identifiers will be transcribed, appear in the notes of our discussion, or any reports.

So let's start here (to the moderators left) and go around the table—please, tell us who you are and where you work.

2. Overview of topic

The moderator should prepare for the session by reading the attached background and purpose of the study. The focus group will serve as an opportunity for local health care providers to discuss their perception, involvement, understanding, and educational needs

regarding pediatric environmental health issues on the Flathead reservation/Lake County. The assistant will capture verbal responses as well as non-verbal communications such as facial expressions, voice tones, and body gestures.

The organizers of this conference have asked us to guide you in a discussion about your perception, involvement, and educational needs regarding pediatric environmental health issues on the Flathead reservation and Lake County. You were invited because you are a local healthcare provider in this area.

3. Ground rules

The moderator presents the *ground rules* to set the tone of the discussion and encourage equality and inclusion of different points of view between participants.

So here are some basic ground rules to guide our discussion:

- **Make sure your cell phone is turned off.**
- **There are no right or wrong answers.**
- **All input is valued.**
- **Everyone is encouraged to provide their thoughts about each question.**
- **If you have an idea that differs from one that is offered by someone else, you are encouraged to express your thought.**
- **Feel free to ask a follow-up question or request clarification from a co-participant.**
- **No response will be identified or attributed to any one individual.**
- **It is my job as moderator, to keep our conversation moving along so we finish on time and allow everyone an opportunity to participate.**

4. Opening question

Allow each participant to answer this question. Direct the question to each participant.

We are going to go around the circle, and everyone is going to be given the opportunity to provide "one word" or "a phrase" in answer to this question.

1. **When I hear the phrase "environmental health" I think of_____.**

5. Continue with questions 2-10.

Here are some tips for keeping the discussion moving along smoothly:

- Allow for a maximum of 10 minutes for each question, including follow-up questions.
- Ask probing questions to clarify a point or request more information.
    - Would you explain further?
    - Can you give us an example?
    - Would you say more?
    - Tell us more.

    - Say more about that.
    - Is there anything else?
    - Please describe what you mean.
    - I don't understand. Could you clarify what you mean.
- Encourage the expression of different points of view.
    - Does anyone see it differently?
    - Has anyone had a different experience?
    - Are there any other points of view?
- Try to avoid feeling uncomfortable with silence. A 5-second pause after a participant comments, could allow people thinking about what was just said, to contribute their thoughts.
- Think about how you might manage dominant talkers, shy participants, experts, or ramblers.
- Promote a conversational tone when you ask the questions and as you listen to the responses.
- Be aware of your non-verbal response tendencies. Avoid gestures (rapid head movements) or comments that could be interpreted as approval, disapproval, agreement, or disagreement like: "Yes" "Excellent" "That's good" since any comment could be interpreted as a judgment.
- Do smile, relax, and nod slowly to communicate warmth and caring and encourage the dialogue.
- Subtly watch the time in order to cover all the questions.

Reference:
Krueger, R. & Casey, M. (2009). *Focus groups: A practical guide for applied research* (4th ed.). Thousand Oaks, CA: Sage.