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but because the Community Health Representatives live it. I am indebted to the Health Committee and Tribal Council of the Standing Rock Sioux tribe for permission to complete this study as a non-Indian (a Wasichu). I acknowledge this privilege with humility.
To Dr. Christine Burd,

Mr. John Eagle Shield,

And

The Standing Rock Community Health Representatives
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ABSTRACT

The World Health Organization (WHO) primary health care model emphasizes intervention at the home and family level, partnerships with the community, collaboration with lay community health workers, and prevention. Thus, the model has significance for nursing. Among the population groups in the United States, American Indians show the greatest disparity from the norm in access to health care and outcomes of care.* This study addresses the primary health care principle of community involvement in health using an empowerment model, with a participatory action research approach, informed by the ethnonursing method of Madeleine Leininger. The population of interest is American Indian community health representatives of the Northern Plains.

Group interviews and individual interviews of community health representatives (CHRs) were analyzed for culture care values, beliefs and practices, which reflect empowerment of CHRs to care for their people. The implications of nurses working with indigenous outreach workers to improve the health of communities were identified. Relevant research from the social and health sciences is critiqued.

* The terms American Indian, Native, and Indian are used instead of Native American, as is common in the language of the Northern Plains tribes.
CHAPTER ONE
PROBLEM STATEMENT

This researcher was interested in discovering the culture care values, beliefs and practices observed in empowerment of American Indian community health representatives (CHR). This interest resulted from attempts to implement the primary health care (PHC) model of the World Health Organization (WHO, 1978) in the health care of underserved populations in the United States, in particular American Indians of the Northern Plains. A discussion of the history of the primary health care model, its application in the United States and around the world, and its significance to nursing follows.

History of Primary Health Care

The evolution of PHC originated in the 1960's and 1970's as a result of criticisms to the “top down,” vertical approach of medical control of health services (Cueto, 2004), the health care model used before the 1960’s. The vertical approach had been successful in programs such as the eradication of malaria. However, experts in international health began to attribute health development to non-medical factors such as poverty, nutrition and environment. Representatives of the Christian Medical Commission, WHO, and the United Nations Children’s Fund (UNICEF) began promoting new approaches to health development as “alternatives” to traditional medical care, drawing on community-based models from developing countries. The framework of PHC can be traced to publications
such as *Health by the People* (Newell, 1975), *A New Perspective on the Health of Canadians* (Lalonde, 1974) and *Alternative Approaches* (World Health Assembly, 1975).

In 1978, representatives of 134 member states of the WHO, 67 organizations, WHO agencies and non-governmental organizations (NGO’s), influenced by the developing literature on alternative approaches to health development, gathered in Alma Ata, the capital of Soviet Kazakhstan. Through plenary sessions and committees, the attendees endorsed the “Alma Ata Declaration,” a set of twenty-two recommendations to governments and organizations for improvement of the health of populations around the world (Reid, 1988). The WHO Alma Ata Declaration was part of the WHO initiative, “Health for All by the Year 2000,” and “Health for All” (HFA) became the clarion call of national population-based health planning in countries all over the world (Bryant, 1988). Equity was the operative principle in PHC and HFA, a commitment to eliminating the existing gap between the “health haves” and the “health have-nots” (Mahler, 1978).

PHC was implemented across the globe, although minimally adopted in the United States. The definition of PHC, adopted at Alma Ata follows:

Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. (WHO, 1978, p. 3)

Five principles of primary health care include: (a) equitable distribution, which refers to equal access to health care, reaching the home and family level; (b) community involvement in health, which refers to grassroots, self-determined, community identification of needs and priorities; (c) appropriate technology, which includes
affordable supplies and equipment, facilities and pharmaceuticals; (d) focus on
prevention, which refers to environmental and behavioral determinants of health, such as
access to clean air and water, substance use and abuse, nutrition and interpersonal
relationships; and (e) a multi-sector approach, which includes all branches of
government, NGOs, business and economic development entities (WHO, 1978).

The Alma Ata Declaration affirmed the WHO definition of health as “a state of
complete physical, mental and social well-being, and not merely the absence of disease or
infirmity” (WHO, 1978, p.2). The Declaration also linked health to social and economic
development. The first International Conference on Health Promotion, which met in
Ottawa, Canada in 1986, reemphasized the connection between health and socioeconomic
and environmental factors. The outcome of this meeting was known as the “Ottawa
Charter for Health Promotion,” and identified actions necessary to achieve Health for All
by the year 2000 (WHO, 1986). The Ottawa Charter states:

To reach a state of complete physical, mental and social well-being, an
individual or group must be able to identify and to realize aspirations, to
satisfy needs, and to change or cope with the environment. Health is,
therefore, seen as a resource for everyday life, not the objective of living.
Health is a positive concept emphasizing social and personal resources, as
well as physical capacities. (p. 425)

The Ottawa Charter identified prerequisites for health as peace, shelter, education,
food, income, a stable eco-system, sustainable resources, social justice, and equity
(WHO, 1986). The Ottawa Charter transcended the individual level of risk analysis and
intervention in the promotion of health to the population level. This set the stage for the
development of the construct of community empowerment for health as an interpretation
of the second principle of PHC, community involvement in health.
One conceptualization of community involvement in health, as a key principle of PHC, developed over time to become “community empowerment for health” (Israel, Checkoway, Schulz, & Zimmerman, 1994; Laverack & Wallerstein, 2001; Wallerstein, 1992). Health education as a discipline initially focused on changing individual health behaviors (Israel, Checkoway, Schulz, & Zimmerman, 1994). Recognition of the impact of social and environmental stress on individual health spurred health educators to focus more on community efforts for social change. Himmelman (1996) identified that community participation in common efforts can occur on a continuum from activities focused on community betterment to community empowerment. Community betterment implies participation with externally controlled development efforts. Community empowerment involves a real acquisition of power in a political sense by traditionally disenfranchised groups.

The Cornell Empowerment Group (1989) defined empowerment as “an intentional ongoing process centered in the local community, involving mutual respect, critical reflection, caring, group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources” (p. 2). Perkins and Zimmerman (1995) identified that community empowerment “refers to collective action to improve the quality of life in a community and to the connections among community organizations” (p. 571); or more simply put, it is “a process by which people gain control over their lives, democratic participation in the life of their
community {Rappaport, 1987}, and a critical understanding of their environment {Zimmerman, Israel, Schulz, Checkoway, 1992}” (p. 570).

United States Perspective

On the tenth anniversary of Alma Ata, an editorial in the New England Journal of Medicine by Chen and Cashman (1988), illustrated how the medical establishment in the United States at that time viewed primary health care. The authors characterized Alma Ata as a strategy for the Third World, citing “American affluence and the power of American science and technology” (p. 947). They claimed the United States had a moral imperative to share the wealth beyond its borders and reach out to developing nations, in a kind of “white man’s burden.”

The assumption that PHC is applicable only to the poorest countries is false, considering the record of implementation in many developed countries, such as Canada (Association of Ontario Health Centres) and Australia (Watts, 1990; Hecker, 1997). Grace (1995) calls the constraints placed on nurses who are implementing PHC in the United States “medical colonialism.” The WHO (1988) publication, From Alma Ata to the Year 2000: Reflections at the Midpoint, expressed similar concern over implementation of PHC in industrialized countries:

It should be kept in mind that Europe, like North America, has been having and continues to have serious problems in paying attention to promotive and preventive aspects of health in the face of burgeoning clinical technology and the depersonalization of medical care. The question remains open as to how much can be accomplished along the lines called for by HFA without a radical reorientation of health perspectives away from the medicalization of health that is currently dominant. This is all the more reason for the importance of this concerted effort by health leadership in Europe to develop a regionwide HFA strategy. (p. 22)
“Medicalization” is a neologism coined by Illich (1982), who saw medicine in the historical process of disabling people to care for themselves. Illich likened the medicalization of health as similar to the motorization of transportation, which caused people to rely on machines and highways, instead of personal locomotion. Cultural iatrogenesis was the effect of medicalization, when it degraded people’s cultural coping (people’s ability to use natural remedies to fight disease) in the art of living (de-emphasized healthy living and emphasized medicine to control disease), suffering and dying, according to Illich.

Significance to Nursing

The PHC paradigm opened up a world of possibilities for nursing. Mooney (1995) clearly differentiated PHC from what she calls the “bio-technical-medical” model of health care. Mooney linked PHC with the history and practice of public health nursing. She emphasized WHO’s call for community planning for essential services such as nutrition, sanitation and prevention (WHO, 1986). Watts (1990) and Schoenhofer (1995) focused on the role of the community as a determinant of health. Self-determination, democratic process and power became important in their conceptualization of PHC including a clear role for nursing. PHC described guiding principles and a process and was not limited to a kind of service.

Prior work by the author identified PHC as significant as a nursing model, and demonstrated the usefulness of applying PHC to underserved populations in the United States (Henly, Tyree, Lindsey, Lambeth, & Burd, 1998; Tyree, Henly, Schauer, & Lindsey, 1998). The University of North Dakota (UND) Nursing Center was started in
1993, based on the PHC model. The UND Nursing Center philosophy stated the belief that “health care should be fiscally and geographically accessible to all persons.”

Further:

The recipient of service has an integral right and responsibility for personal health care decision-making and should be supported in self-advocacy. In approaching the individual, family and community we acknowledge variations in culture and lifestyle, and seek competence in increasing acceptability of services in a milieu of diversity. We view empowerment for health as a natural state of individuals, families and communities, not derived from professional disciplines. We further believe that recipients of health services have the right to guidance and assistance with needs which are not problem or illness related, for the sake of primary prevention; and that a facilitating professional posture demonstrates that value. (Henly, Tyree, Lindsey, Lambeth, & Burd, 1998, p. 26)

Orchard and Karmaliani (1999) proposed a role for nurses prepared at the masters level as “community development specialists” for developing countries. They asserted that implementation of PHC in some countries was impeded by the over-supply of physicians who reinforced the curative model of care. They believed that the challenges of organizing a community to achieve health required advanced practice nursing and titled the proposed specialty “Community Development Nurse Specialists” (CDNS). Their proposal recognized the complexity and long-term nature of the endeavor, a view supported by the literature on community empowerment for health.

**American Indian Population**

The Aberdeen Area of the Indian Health Service (IHS) includes 18 tribes of American Indians in North Dakota, South Dakota and Nebraska. The common designation of “Sioux” is applied to bands of Dakota, Lakota and Nakota, which are linguistically separate based on the use of the letters “d” “l” and “n”, among other differences (Schneider, 1994). The state of North Dakota includes three federally
designated reservations of Sioux within its borders, while South Dakota includes seven reservations of Sioux Indians. Other tribes may be represented in the populations through intermarriage or migration, and some enrolled members of these tribes live off the reservations.

Differences in mortality rates between American Indians for 1998-1999 and for all races in the United States population for 1995, the most recent data available, demonstrate ...

1. alcoholism - 627 percent greater
2. tuberculosis - 533 percent greater
3. diabetes mellitus - 249 percent greater
4. accidents - 204 percent greater
5. suicide - 72 percent greater
6. homicide - 63 percent greater (Indian Health Service, 2004, p. 6)... than those of the general population.

Community Health Representatives

Community empowerment for health must also reach the home and family level in order to be effective. CHRs on United States American Indian reservations are one type of outreach. They are community health workers and the focus of this study. CHRs bridge the gap between the western medical model and more traditional health care meanings and practices (Satterfield, Burd, Valdez, Hosey, & Eagle Shield, 2002). Indigenous workers are key to achieving the PHC principle of community empowerment for health.
CHRs began functioning as outreach workers through the Indian Health Service (IHS) in 1968 (Dixon, 2001). Their role is to work between the systems of local, indigenous health knowledge and practices, and professional, medical care. CHRs provide social support. They improve access to services by taking care into homes and into the community, transporting patients to clinics and hospitals, and facilitating communications between providers and tribal members (Satterfield, Burd, Valdez, Hosey, & Eagle Shield, 2002).

In a study of lay health workers as “Community Health Advisors” at the University of Arizona (1998), seven common roles were identified: (a) cultural mediation between communities and health service systems; (b) informal counseling and social support; (c) provision of culturally relevant health education; (d) advocacy for individual and community needs; (e) assurance that people get the services they need; (f) building of individual and community capacity to promote health; and (g) provision of direct services.

**Domain of Inquiry**

The domain of inquiry of this study is the culture care values, beliefs, and practices observed in empowerment of American Indian community health representatives.

**Research Questions**

1. What influences do worldview, ethnohistory, religious, and philosophical factors have on culture care practices of community health representatives?
2. In what generic care practices do community health representatives engage?
3. In what professional care practices do community health representatives engage?

4. What are the values and beliefs of American Indian community health representatives with respect to generic and professional nursing care and practice?

5. What culture care values, beliefs, and practices described by community health representatives indicate the presence of empowerment?

Significance to Theory of Culture Care

This study will expand the knowledge base of culture care values, beliefs and practices of American Indian CHRs of the Northern Plains. There are few studies of this type and limited research with CHRs in general. If community empowerment for health, as promoted by WHO, contributes to improved health, it would be well to know whether American Indian CHRs perceive that they are empowered to provide quality health care and disease prevention to their people. CHRs must be empowered to deliver quality care. To do otherwise, risks imposing values and beliefs of the culture of the providers of the dominant health care system onto the American Indian people (Leininger, 1997).

Madeleine Leininger (1991) developed “Culture Care Diversity and Universality” as a theory of nursing. In doing so, Leininger deviated from the emphasis in nursing on the nurse-patient relationship as the dominant paradigm of nursing. Leininger posited care as the central phenomenon of nursing. She recognized that the phenomenon of care could be trivialized because of its pervasive use in language. However, Leininger believed the very ubiquitousness of care in human life demonstrated its core significance.
as a phenomenon of interest for nursing research. Leininger differentiated generic and professional care. Generic care, emic, referred to folk, natural and lay care practiced within cultures. Professional care, or etic, was care learned by nurses prepared in schools of nursing and practiced in professional contexts. Leininger saw both generic and professional care as existing within cultures. Through her work, Leininger (1997) intended to move nursing from an ethnocentric, unicultural position to a multicultural knowledge base.

**Philosophical and Epistemological Basis**

Culture Care Diversity and Universality was derived from the ontological basis of anthropology and the philosophical base of existentialism (Leininger, 2001). Ethnonursing was the research method Leininger developed to explicate phenomena of interest to nurses. The ethnonursing method is inductive and naturalistic (Leininger, 1985). Ethno is a Greek root word that refers to “the people.” Care is the phenomena Leininger defined as the essence of nursing. Knowledge development using the ethnonursing method is “grounded with the people as the knowers” (2001, p. 84), in the naturalistic setting. The “Sunrise Enabler” in Appendix A is a tool that graphically illustrates the elements of inquiry with the ethnonursing method.

**Assumptive Premises**

Leininger (2001) identified 13 assumptive premises “to guide nurses in their discovery of Culture Care phenomena” (p. 44). The assumptive premises of particular significance in this study are:
1. Culture care concepts, meanings, expressions, patterns, processes, and structural forms of care are different (diversity) and similar (towards commonalities or universalities) among all cultures of the world.

2. Every human culture has generic (lay, folk, or indigenous) care knowledge and practices and usually professional care knowledge and practices which vary transculturally.

3. Cultural care values, beliefs, and practices are influenced by and tend to be embedded in the worldview, language, religious (or spiritual), kinship (social), political (or legal), educational, economic, technological, ethnohistorical, and environmental context of a particular culture.

4. Culturally congruent or beneficial nursing care can only occur when the individual, group, family, community, or culture care values, expressions, or patterns are known and used appropriately and in meaningful ways by the nurse with the people.

5. Culture care differences and similarities between professional caregiver(s) and client (generic) care-receivers exist in any human culture worldwide.

6. The qualitative paradigm provides new ways of knowing and different ways to discover epistemic and ontological dimensions of human care transculturally. (pp. 44-45).

Ethnonursing

The ethnonursing research method of Madeleine Leininger (1997) is the method chosen to inform this participatory action research study. Ethnonursing was selected
because it is based on a theory of nursing and explicates phenomena of interest to nurses. It thereby builds nursing knowledge. At the time when Leininger was developing her transcultural nursing theory and research method in the 1950's and 1960's, she saw nurses invested in serving medicine and not focused on caring, which she considered nursing’s essential function (Leininger, 1997). James Spradley (1979, 1980) was Leininger’s classmate in the anthropology doctoral program at the University of Washington, and her ethnonursing research method is consistent with Spradley’s ethnographic methods (Leininger, 2001). Leininger (1990) described ethnonursing as “the study, documentation, and analysis of the local or emic peoples’ viewpoints, beliefs, and practices about actual or potential nursing care phenomena of particular cultures to generate nursing knowledge” (p.46).

Participatory Action Research

Empowerment is a goal of participatory action research. Seng (1998), in her article, “Praxis as a Conceptual Framework for Participatory Research in Nursing,” described a process, which “addresses the political aspects of knowledge production and emphasizes ongoing power analysis and consciousness-raising” (p.39). Seng discussed a history of praxis, from ancient Greek origins of the word through Kant, Marx, Gramsci and Lukacs, and focused on a wider explication of the work of critical educator, Paulo Freire (1987). The implication in using praxis, as a framework for participatory action research, was that action would evolve from information giving and consciousness-raising. On one level action can be anticipated from the researcher herself. On another level success would be measured by action by the community to improve health through
a variety of strategies. In research based on praxis, the researcher is an active participant in the process under question, in this case, improving health.

Flaskerud and Anderson (1999) used the term “participant-focused research” to describe the method in which participants collaborate as full partners in the research process. Flaskerud and Anderson acknowledged the variety of titles applied to similar methods, including “collaborative inquiry” and participatory action research. Participant-focused research involved open and transparent development of research questions and approaches to data gathering with an ultimate goal of generating action aimed at improving health.

The Aberdeen Area Tribal Chairmen’s Health Board (2005) has established participatory action research as the standard for research with American Indians in the Aberdeen IHS Area. Participatory action research is a method, which maximizes participant autonomy and welfare (Khanlou & Peter, 2005). Process steps representative of participatory action research with American Indians are illustrated in Appendix B.

History of the Effort

In 1996, representatives of the University of North Dakota (UND) Nursing Center, and the Recruitment and Retention of American Indians into Nursing (RAIN) project began meeting with staff of the North Dakota State Diabetes Control Office and a South Dakota IHS physician via telephone conferences. Dr. Christine Burd (1995) of the UND Nursing Center had recently completed her doctoral dissertation at the University of Manitoba on lower extremity amputation, secondary to diabetes mellitus, in the Aberdeen Area IHS. The motivation of the State and IHS staff was to influence
physician practices in North Dakota to achieve better management of diabetes. The UND nursing participants worked to reframe the discussion toward involving nurses on the community level. One outcome of this effort was the appointment of regional diabetes control nurse consultants. Another outcome was an invitation to an IHS foot care conference in Bismarck, North Dakota, in November, 1996. The link with CHRs began at the end of this conference.

As the conference hall emptied out at the end of the conference, a group of eight CHRs approached the stage where the presenters, including our IHS collaborating physician, remained. Mr. John Eagle Shield, Director of CHRs at the Standing Rock Reservation and Chair of the Aberdeen Area CHR directors’ group, addressed the physician asking, “When are you going to help us control the effects of diabetes among Indian people?” The physician replied, “Talk to the nurses,” and pointed to the author, who had also approached the stage at that time. Mr. Eagle Shield stated, “I don’t want to talk to the nurses. I want to know when you are going to help us control the effects of diabetes among Indian people.” The physician reiterated, “Talk to the nurses.” After asserting the nurses couldn’t help once more, Mr. Eagle Shield described his wish to the physician to have CHRs reimbursable as nurse aids or certified as diabetes educators.

Four months later, Mr. Eagle Shield drove the six hours from Standing Rock to Grand Forks to meet with UND Nursing Center representatives, the IHS physician, a podiatrist, a nurse certified diabetes educator from the Turtle Mountain Chippewa Reservation, and, by telephone, the North Dakota State Diabetes Control Officer. A plan was developed to train CHRs as “Tribal Diabetes Educators.” A distinction must be
made that tribes employ CHRs, and the Indian Health Service employs IHS staff. Both are funded by IHS, but have different levels of accountability to the tribes.

At the start of the partnership between the UND Nursing Center and the CHRs in 1996, approximately 60 individuals in the Aberdeen Area Indian Health Service were subjected to lower limb amputation. The most recent data available, from 1988, showed among the Sioux that: (a) the diabetes rate was 3.7 times the United States rate; (b) end stage renal disease was 4.8 times greater than the American-Indian/Alaska-Native rate, and 13.4 times the rate for whites in the United States; (c) the age-adjusted incidence rate for lower extremity amputation of 86.7/10,000 diabetic population was 1.5 times higher than the United States rate; and (d) the proportion of diabetes-related lower extremity amputation, 84%, was 1.8 times higher than the general United States population rate of 45% (Stahn, Gohdes, & Valway, 1993).

In March 1997, Dr. Burd began meeting with Mr. Eagle Shield, and the IHS diabetes coordinator and dietician at Standing Rock, approximately every two to three months. The telephone conferences begun in 1996 continued, now with participation by CHRs. In August, 1997, the North Dakota State Diabetes Coordinator brought his Centers for Disease Control and Prevention (CDC) supervisor, Dawn Satterfield, RN, from the national Diabetes Control Project to Standing Rock for an all day meeting. Satterfield had conducted focus group interviews with American Indian people in Montana tribes. This began long-term involvement by the CDC in the effort, and Satterfield’s continuous involvement in training and consultation, including her eventual “adoption” by an Indian family.
Background data was available from a community assessment conducted in 1995, by the North Dakota and South Dakota State Departments of Health, the Standing Rock Sioux Nation, which straddles both states, and the IHS entitled “Diabetes Today.” This joint effort brought 25 people together for two days to create a community profile, and identify the complications of diabetes in the population. Data on lower extremity amputation derived from Burd’s dissertation were distributed at an IHS foot care conference for CHRs in 1995, further heightening awareness of the complications of diabetes among several sectors.

In May 1997, UND Nursing Center staff collaborated with the existing professional and tribal partners to submit a proposal for federal funding. The intent of the grant proposal was to create a diabetes complication registry, particularly focused on: (a) screening for foot care and prevention of amputation, and (b) screening of people with microproteinuria and prevention of renal failure in two IHS service areas; Rapid City, South Dakota; and Belcourt, North Dakota. The grant was not funded, but the partnerships were strengthened in the attempt. At this time the terminology “Diabetes Today: Phase 2” and “Northern Plains Diabetes Consortium” began to be used to describe the effort. The focus of Diabetes Today: Phase 2 was to have CHRs leading the community toward meeting the goals of “Diabetes Today” to reduce complications of diabetes. The consortium was a loosely coupled collaboration of the Diabetes Control Project of North Dakota, IHS personnel, reservation diabetes coordinators, tribally hired CHRs, and the UND Nursing Center.
Also in 1997, Wellness Associates (1997), the North Dakota State Diabetes Control Project, authorized nonscientific focus group interviews related to diabetes among people with diabetes and physicians who treat diabetes. Participants interviewed were members of two tribes, the Turtle Mountain Chippewa and the Spirit Lake Dakota with four participants from each tribe. Themes discovered that related to diabetes were: (a) a view that it is “very common,” (b) a belief that diabetes has resulted from changes to traditional lifestyles and diet, (c) that individuals need to “take care of themselves” and not rely on others, (d) that diabetes educators are needed to supplement physician services, (e) that specialty clinics and dietician services help in provision of care on a regular basis, since there is less physician turnover in these areas, (f) that “Indian medicines” are not used for diabetes, although they are used for other health problems, and (g) that stress increases the difficulty of managing diabetes. No links between diabetes and tobacco or alcohol use were mentioned.

In the fall of 1997, Dr. Burd began regular meetings with the Cheyenne River Sioux Tribe (CRST) in South Dakota, the second reservation that had participated in the original Diabetes Today community assessment. These planning meetings included the CRST Community Diabetes Educator, and the Tribal Health Director for the CRST. Regional and national attention became focused on the progress of these meetings.

In April, 1998, five members of the “Northern Plains Diabetes Consortium” including two CHRs were invited to share the “Diabetes Today: Phase 2” plan at three conferences; the CDC Diabetes Translation Conference in Tampa, Florida; the Dakota Conference on Rural Health in Fargo, North Dakota; and the National Indian Nursing
Education Conference in Grand Forks, North Dakota. Two CHRs were invited by the CDC to Atlanta, Georgia to the National “Diabetes Control is Prevention” Satellite Broadcast in October, 1997.

On the local level, at Standing Rock, CHRs were invited to do a diabetes screening on the premises of the IHS Clinic, and IHS and CHR personnel began to have meetings more regularly. A plan was developed to conduct a “Powwow for Diabetes” in the summer of 1998. A foot registry was initiated at the Turtle Mountain Chippewa Reservation in Belcourt, North Dakota, by a UND RAIN nursing student who spent eight weeks with the nurse diabetes educator in the summer of 1997. At CRST a masters-prepared RAIN graduate nurse coordinated the screening of half the population of children for height, weight and acanthosis nigricans, a skin manifestation of obesity and diabetes often observed on the back of the neck. The screening program included a plan to offer a fitness program.

While these developments appeared to be taking place at lightening speed, they were in fact the result of many telephone calls, lengthy discussions and, sometimes, implied requests embedded in stories. This can be illustrated by a project to place exercise equipment at Standing Rock. In a conversation about the link between exercise and diabetes, Mr. Eagle Shield gave Dr. Burd a copy of a letter addressed to whom it may concern, signed by American Indian Vietnam war veterans, in which they requested exercise equipment. The veterans didn’t know who to send the letter to. They were simply expressing a need. Mr. Eagle Shield didn’t elaborate on the letter. It was Dr. Burd’s challenge to respond to the request. The UND Nursing Center staff did respond to
the request by submitting a proposal to a small foundation for $10,000., which was funded.

Dr. Burd obtained funding from the regional Bremer Foundation and in 1998, the first one-week intensive training sessions were held for Aberdeen Area CHRs at the UND College of Nursing. Eighty-three CHRs completed the basic training in diabetes control and prevention, and several attended refresher classes over the four years of the project. There have been numerous spin-offs of the initial effort to train CHRs as diabetes educators including transition to tribal college locations for training, the granting of tribal college credit, and other reservation-based major diabetes projects funded with Dr. Burd’s consultation and evaluation. The activity related to diabetes on reservations has grown exponentially. This researcher has been more peripheral to the effort as consultant to Dr. Burd, Nursing Center administrator, and participant-observer in some training sessions and meetings. This study is based on ten years of work among American Indians of the Northern Plains aimed at reducing complications of diabetes. The work was not undertaken with research intentions, but as service based on explicit requests of CHRs.

Summary

This is a participatory action research study informed by the ethnonursing method of Madeleine Leininger. The domain of inquiry of this study is the culture care values, beliefs, and practices observed in empowerment of American Indian community health representatives. The researcher’s interest is in application of the primary health care model of the World Health Organization. The specific PHC principle of community
involvement in health was studied as a reflection of community empowerment for health. The study builds on ten years of work by UND Nursing Center personnel with CHRs of the Northern Plains, responding to their request to decrease the incidence of complications of diabetes among Indian people.
CHAPTER TWO
LITERATURE REVIEW

Ethnohistory

The Dakotas are part of a large grassland habitat called the Great Plains, which bisect the central United States north to south. Early inhabitants of the plains were nomadic hunter-gatherers who depended on the bison for food and furs, and sedentary horticulturalists, people who raised food. Three eighteenth to nineteenth century phenomena decimated the Indian tribes: (a) epidemics of smallpox, measles, whooping cough and influenza depopulated tribes, more so when they affected men and women in the reproductive years; (b) depletion of the food source of bison occurred with the rise of the fur trade; and (c) the Montana gold rush resulted in suppression of tribes by the United States military, protecting the influx of settlers from raiding parties of American Indians who saw their land rights threatened (Decker, 1991).

The policies of the United States federal government to assimilate the Indian people and allotment (parceling of Indian land) had disastrous effects on the survival of the American Indian people and their culture. In the nineteenth century, the forced removal of tribes in the East to lands west of the Mississippi opened the eastern half of the country to European settlers. In the resolution of the conflict between colonists and the Indian people over land, with the eventual defeat of all of the tribes, reservations were developed and ceded (allotted) to the tribes. Reservation land was usually of the poorest
quality for farming or grazing (Zechetmayr, 1997). In those instances when gold was discovered on reservation land, tribes were simply moved off what then became highly prized land.

Land allotments on reservations were too small to sustain the American Indian populations settled there. The United States government retained the obligation to help the American Indians subsist under trust responsibility defined by treaties. When providing food became too expensive for the government, assimilation became the federal policy to “mainstream” American Indians, make them behave as white settlers, and develop self-sufficiency. This disrupted traditional life-ways and dietary practices. Likewise, allotments to male heads of families disrupted the communal nature of American Indian society, which was sometimes matrilineal, replacing it with the practice of private property ownership of individual plots of land (Shelton, 2001).

Some traditional knowledge and practices of Native healing were lost with the death of indigenous practitioners in the calamity of depopulation. Traditional spiritual and health practices were further suppressed by the 1883 Rules Governing the Court of Indian Offenses of the Department of the Interior, which designated the practices of medicine men as “Indian offenses,” and outlawed healing ceremonies, such as the Sun Dance. Other assimilation policies included the funding of religious mission schools, Bureau of Indian Affairs (BIA) boarding schools, and registration of American Indian children in white public schools, all of which suppressed Native languages and culture. The legacy of these assimilation policies has included high rates of alcoholism,
depression, suicide and domestic violence among American Indians compared to the general United States population (Shelton, 2001).

The earliest United States government health services for American Indians were focused on control of communicable diseases among groups living near military installations, in order to protect the soldiers. The first congressional appropriation for Indian health care was in 1832 for the purchase and administration of smallpox vaccine (Cohen, 1982). Between that time and the present, a series of government agencies, reports and reorganizations have failed to adequately address the dire realities of health problems among American Indians (Dixon, 2001).

Disparities in health status between American Indians and the general population have persisted for 500 years (Jones, 2006). Over the years, explanations for these disparities have included; divine providence, immorality, personal choice, and genetics, among others. Jones concluded his historical tracing of speculation regarding the cause of health disparities among Indians with the suggestion that disparities in wealth and power since colonial times were the determining factors in the persistence of poor health and should be the focus of research in Indian health.

_American Indian Culture Care Values and Meanings_

Previous studies of American Indian culture care values and meanings apply to this Domain of Inquiry. Struthers’ (2000) study of Ojibwa and Cree Woman Healers posited that the healing gift was within an individual healer, given the healer by the Creator, and learned from previous generations of healers and the community. Belief in the power of the gift of the Creator to work through the healer was necessary for the
healing to work. "Wholesome use of self" in the healing process included prayer, the healing circle, the medicine wheel, and the sweat lodge, among other roles and traditions. A realization of the oneness of an individual with creation including access to spirits was fundamental to the effectiveness of the healing process. Native language was also important. Being balanced and living by the circular medicine wheel of life was necessary for the healer to be effective. Embracing all of humanity bespeaks openness to other cultures and ways different from one’s own.

Spirituality is very important in everyday life among Navajo and Sioux people (Sanchez, Plawecki, & Plawecki, 1996). This increases the importance of prayer, ceremonies and rituals in healing. Traditional remedies include curative plants, products of the earth’s vegetation. Professionals from other cultures should be aware of the “five great values,” generosity and sharing, respect for the older ones, getting along with nature, individual freedom, and courage.

Intra-cultural variation was identified among three Canadian Anishinaabe communities regarding their explanations for the cause of diabetes (Garro, 1996). Recognition of diabetes was a fairly recent discovery among the people and it was frequently termed, “white man’s illness.” One theory was that people’s individual food choices and too much “sweets” caused diabetes. Differences of opinion were expressed as to whether alcohol could be considered a “sweet.” Another explanation tied the development of diabetes to larger societal issues resulting from the destruction of Native culture. Some people thought the visiting nurse spread the condition with the needles
used to vaccinate. Similar disagreement occurred over the question of whether diabetes ran in families.

In a 1993 study of encounters between public health nurses and clients on American Indian reservations during the 1930's, Abel and Reifel (1996) identified selective participation by clients in the nurses' recommended health practices, and resistance to rejected ideas about health. The study examined reports filed by the nurses, which demonstrated a high level of ethnocentrism on their part, and oral histories of their living clients on two Sioux reservations in South Dakota. The mission of the nurses emerged as one of assimilation and the inculcation of Euro-American values among the clients. A value, which the clients expressed about healers, was that it was necessary that a healer be a "good person," interested in helping people, and the nurses were most often seen that way. Nurses were received in the home with hospitality consistent with the Sioux culture. This often meant engaging in practices valued by the nurse, but not the client family, such as sweeping the dirt floor of the home. Among the valued services of the nurses to the clients were the dispensing of medications and immunizations. These resembled the practice of using botanical remedies to the clients. The nurses sought to institutionalize health care in the Western model such as with the development of hospitals and control of birthing practices. The clients' motivation was to complement traditional healing with selected Western methods. Hospital delivery of infants contradicted specific beliefs about the importance of birthing in the presence of the extended family of loved ones, and was rejected.
Summary

The importance of addressing cultural values, beliefs and meanings in programs of health promotion is very evident in these studies. Further, the research provides clues for interpretation of verbal and nonverbal communications among the group under study. The ethnohistory of American Indians of the Northern Plains is an important context for understanding the cultural and social structure influences on the population.

Empowerment

Psychological Empowerment

Empowerment can refer to an intra-psychic phenomenon of an individual or an attribute of a group. The word has become popular in the common parlance and this has confused its meaning. As defined by Rappaport (1987), empowerment is “a mechanism by which people, organizations and communities gain mastery over their affairs” (p. 122). Perkins and Zimmerman (1995) describe empowerment as a construct, which “links individual strengths and competencies, natural helping systems, and proactive behaviors to social policy and social change” (p. 569).

Community Psychology

The discipline of community psychology grew out of applied psychology, which came into its own following the return of veterans from World War I and II (Rappaport, 1977). Community psychology was focused on “deviants” in society and the development that was needed in individual treatment of mental illness outside of mental institutions, community acceptance of mental illness and the knowledge and skills of the helping professions, such as medicine, nursing and psychology. The community mental
health movement of the 1960’s and ‘70’s reflected this two-pronged approach of treating mental illness of individuals and changing community attitudes toward mental illness as the context of treatment. Empowerment was the central issue of concern in the field of community psychology.

Empowerment in a multi-site statewide social service agency was studied using a constructivist approach (Foster-Fishman, Salem, Chibnall, Legler, & Yapchai, 1998). State level administrators had implemented an employee empowerment strategy one year before the study began. The researchers found employee empowerment evolved through a diverse set of pathways, including opportunities for autonomy, freedom to be creative, knowledge development, feeling trusted and respected, experiencing fulfilling work, and input to decision-making. Employees increased their level of control in various forms within any one pathway, according to their own values and beliefs. How individuals combined pathways to achieve increased control and power was highly personal, and employees desired different levels of control.

Implications for empowerment interventions included the recognition that leaders’ or researchers’ goals for employee control may not match the employees’ desires for participation. Basing empowerment on employee perceptions and definitions would enhance an initiative to increase empowerment. Opportunities for empowerment should be multi-faceted to allow for individual choice of a pathway. Dynamics in various settings may shift rapidly, creating multiple simultaneous contexts for an empowerment initiative. The researchers concluded that positivist, global measures of empowerment
would be likely to miss the sub-text of complex environments, and qualitative methods were most appropriate and useful for gauging empowerment.

McMillan, Florin, Stevenson, Kerman and Mitchell (1995) studied empowerment praxis in community coalitions. The instruments used were a Task Force Member Survey and Key Informant Telephone Survey. The Member Survey included 173 items assessing demographics, participation level, prevention knowledge and expectations, perceptions of social climate, and a variety of other dimensions. The key informant interview was a telephone survey of the president of the town council, chief of police and superintendent of schools in 35 communities in Rhode Island, the location of the study. The major dependent variable, psychological empowerment was comprised of five scales: (a) perceived knowledge and skill development, (b) perceived participation competence, (c) expectations for future individual contributions, (d) perceived group/organizational accomplishments, and (e) expectancies for future group/organizational accomplishments. Independent variables consisted of: (a) demographics; (b) perception of community variables; (c) sense of community; (d) participation variables, hours, roles, benefits and costs of participation; and (e) organizational variables, involvement/inclusion, task focus, satisfaction level and commitment.

McMillan et al. (1995) established the importance of the organizational context to empowerment, in that the organizational climate variable was the strongest. Task forces differed in the empowerment of their members. The relationship between collective empowering of members of a task force, and the task force itself being empowered, was
demonstrated. The experience of being empowered was less likely to accrue to bystanders than participants. That active individual participation is a major route to achieving empowerment was demonstrated through strong relationships between empowerment and participation variables. Meaningful cross-level connections between organizations empowering of members and empowered task forces were demonstrated.

**Conflict vs. Consensus**

Empowerment is viewed paradoxically as conflict-based and consensus-based. Bush and Folger (1994) described empowerment in a model of “transformative mediation” in the conflict paradigm. A party is empowered through mediation as to goals, options, skills, resources, and decision-making. Himmelman (2001) defined empowerment as, “an increase in the capacity to produce results, or, in the context of community change, as an increase in the capacity to set priorities and control resources that expand self-determination” (p. 282). Consensus-based empowerment takes place through the processes of networking, coordinating, cooperating and collaborating as described by Himmelman (1994, 1996).

**Empowerment and Resource Development**

Saegert and Winkel (1996) studied low-income minority communities with a multivariate approach. Exogenous variables (level 1) were: (a) a seven item subset of the Kobasa Hardiness Scale; (b) continuous-level demographic variables included age, education, number of children under 18, length of residence in the building and income; (c) perceived neighborhood characteristics; and (d) perceived opportunities for participation in the neighborhood. Endogenous variables related to co-op activities (level
2) included: (a) frequency of co-op meetings, (b) informal and formal participation, and (c) a composite measure of perceived participation by other residents. Building quality of life (level 3) included: (a) knowledge of co-op policies and procedures, (b) ability to personally affect what happens in their co-op, (c) building tension, (d) the extent to which the participant felt like an owner or renter, and (e) composite of building satisfaction, building pride and perceived co-op success; empowerment and quality of life (level 4).

In addition, the Zimmerman and Rappaport Empowerment Scale was used, providing an attitudinal measure of empowerment including: (a) leadership style, (b) organizational leadership, (c) political participation, and (d) leadership (I would prefer to lead than follow).

Saegert and Winkel (1996) found that: (a) the aggregate measure of perceived participation of others correlated with building quality, (b) the aggregate measure of building quality influenced empowerment and voting behavior, and (c) personal participation in building activities was a good predictor of empowerment, indicating empowerment operates at both the personal and the group level. They concluded that a sense of community contributes to greater involvement in community activities. Material improvement of the environment enhanced personal and political empowerment. Therefore, empowerment was shown to have a collective and material dimension, in addition to a psychological dimension.

*Empowerment in Social Services*

An organizational ethnography of an early childhood program for families living in poverty by Bartle, Couchannal, Canda, and Staker (2002) found that: (a) focus on
client change and community change are necessarily intertwined and reciprocal, (b) the federal focus on economic self-sufficiency contrasted with the staff recognition of the effects of intangible services such as empathy as being more permanent, (c) individualized services were favored over standardized services by families and staff for sensitivity to family schedules and priorities, (d) peer outreach workers became more professionalized with training, (e) roles of service provider and community activist were shared by case managers and supervisors, (f) the federal government value for economic self-sufficiency contradicted empowerment of families, and (g) standardized federal program requirements impeded family empowerment.

Conclusions drawn from the findings of Bartle et al. (2002) included recognition that: (a) empowerment requires a balance of idealism and practicality, (b) empowerment is a long term collaborative process with clients, (c) staff empowerment is accomplished through a human development model, (d) staff must be flexible in respecting families’ priorities, (e) multiple relationships between staff and families promote empowerment, and (f) it is necessary to move beyond seeing self-sufficiency as independence. On the organizational level, the process of reflection was critical to creative development.

Empowerment and Nursing

In her differentiation of empowerment and advocacy, Canadian nurse researcher and proponent of primary health care, Adeline Falk Rafael (1995), attributed the concept of empowerment to the liberating philosophy and work of Brazilian educator, Paulo Freire (1987), beginning in the 1960’s. Consistent with Freire, Rafael identified characteristics of empowerment as: (a) clients are equal participants in their own
empowerment; (b) the process of empowerment enables increased personal control; (c) it promotes an awareness and commitment to social change; and (d) regarding the other person as subject rather than object.

Rafael (1998) used oral histories and focus groups to explore the relationship between power and care among public health nurses in Southern Ontario. She found three phenomena: (a) ordered caring, which was caring by command of the bureaucracy, (b) assimilated caring, which was assimilation of male medical values, and (c) empowered caring, which emphasized social and cultural change. Rafael proposed a dialectic of power and caring, however, it is unclear whether the caring construct can stand up to the power construct in a dialectic.

A study of British nurses’ views of empowerment by Fulton (1997) used a descriptive survey based on critical social theory. The nurses saw empowerment as involving decision-making, choice and authority. Their experience of decision-making was that of “picking at” the authority of others and they believed they needed visible authority themselves. Their view was that patients do not have real choices. Personal power meant assertiveness to the nurses, not aggressiveness. They experienced difficulties in inter-disciplinary teams, because of the power differential between them and physicians. The nurses identified “feeling right about oneself” as reflecting empowerment, in contrast to having low self-esteem, self-doubt and fears, which would be consistent with an oppressed state.

Fleury (1991) used grounded theory to study 29 individuals initiating and sustaining cardiac risk factor modification programs. Three stages of empowerment were
found in temporal order: (a) appraising readiness, including reevaluating, identifying barriers and owning change; (b) changing, including enacting strategies, creating loopholes, overcoming lapse, self monitoring, affirming; (c) integrating change, creating rituals, achieving harmony, transforming change. Fleury found congruency of themes with nursing priorities for the generation of knowledge of behavior in interaction with the environment, and processes through which changes in individual health status occur.

*Participatory Action Research Studies*

Garwick and Auger (2003) implemented a participatory action research project, the Indian Family Stories Project, with urban American Indians in Minneapolis. The focus of the project was families with a child with chronic illness. On the recommendation of community leaders, five subgroup action plans were developed to address the problem of asthma as a need for which the community had few resources. Among the lessons learned, Garwick and Auger cited the need for the philosophy of the research team to be congruent with the cultural and community context. Continuity and follow-through by the research team fostered trust of community members. A broad network of community representatives needed to be involved in various aspects of the projects.

Taylor (1999) used participatory action research of isolation of minority deaf people in a borough of London. Significant barriers to empowerment of this group existed in their difficulties in communicating with each other, including the fact that 66 minority populations were represented in the borough. A multiplicity of language systems was observed, including variations of sign language and dialects. The action
research succeeded in connecting 15 representatives of minority communities, service agencies, general practitioners and deaf service users in a workshop format. The workshop generated a short term action plan and strategies for improvement of services in the long term. Taylor concluded, “It is not sufficient to simply report the ‘voice’ of the user; it is necessary to theorize the data” (p. 383). It is necessary to relate the “experience of service users to wider social structures” (p. 383). Taylor succeeded in describing the complexity of issues of isolation and identity among minority deaf people, and avoided characterizing these in a simplistic view of oppressor and victim, which is often associated with critical theory.

**Empowerment Concept Analyses.**

Five concept analyses of “empowerment” were found in the nursing literature. These and the author’s unpublished concept analysis are summarized in Table 1.

Cynthia Armstrong Persily, a women’s health practitioner, educator and researcher, and Eugenie Hildebrandt, community health nurse researcher, developed a middle range theory of community empowerment based on the three major concepts of: involvement, lay workers, and reciprocal health (Persily & Hildebrandt, 2003). Involvement was achieved by linking community members to health needs, resources and barriers, and facilitating a collective response via coalition building. Lay workers bridged the professional and indigenous approaches to problem solving. Reciprocal health resulted from mutual, positive efforts of professionals and community members to engage in healthy behaviors.
Table 1. Empowerment Nursing Concept Analyses

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<tr>
<th>Reference</th>
<th>Individual or Community Level</th>
<th>Antecedents</th>
<th>Attributes</th>
<th>Consequences</th>
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<tbody>
<tr>
<td>Gibson, C. (1991). A concept analysis of empowerment. Journal of Advanced Nursing, 16, 354-361.</td>
<td>Individual</td>
<td>NURSING PERSPECTIVE 1. Health belongs to the individual. 2. Individual’s capacity for growth and self-determination needs to be respected. 3. Professionals cannot empower people. People empower themselves. 4. Professionals need to surrender control. 5. There must be mutual respect between individual and provider. 6. Trust is a necessary condition in the process.</td>
<td>NURSING PERSPECTIVE Nurse as sensitizer to self-awareness and self-growth. Nurse as facilitator and resource, instead of provider.</td>
<td>NURSING PERSPECTIVE Nurses: oriented toward macro-social level of health for all; promote accessibility of services and reduce inequalities; support social networks. “Empowerment process involves transformation of consciousness, in which the boundaries of self … become more permeable so that a sense of connectedness results.”</td>
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<td>CLIENT PERSPECTIVE Positive self-concept, personal satisfaction, self-efficacy, sense of mastery, sense of control, sense of connectedness, self-development, a feeling of hope, social justice</td>
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<td>Hokanson Hawks, J. (1992). Empowerment in nursing education: concept analysis and application to philosophy, learning, and instruction. <em>Journal of Advanced Nursing, 17, 609-618.</em></td>
<td>Individual</td>
<td>Nurturing, caring environment; trust, openness, honesty, genuineness, communication and interpersonal skills, acceptance of people as they are, mutual respect, value of others, courtesy, and shared vision.</td>
<td>An interpersonal process characterized by open communication, mutual goal-setting and decision-making, use of empowering methods of educating, leading, mentoring, providing, structuring, actualizing.</td>
<td>Ability to set and reach goals, increased problem-solving ability, better communication and leadership skills, satisfaction with school, improved self-esteem, autonomy and responsibility.</td>
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<tr>
<td>Finfgeld, D. (2004). Empowerment of individuals with enduring mental health problems: Results from concept analyses and qualitative investigations. <em>Advances in Nursing Science</em>, 27, 44-52.</td>
<td>Individual</td>
<td>“lack of power or maladaptation in the balance of power such that oppression exists at the individual or societal level.” Outrage as motivation for change. Ability to acquire knowledge, e.g. of social, political, and economic forces. Individuals as personally responsible. Confidence in beneficent power sharing. Those with power willing to cooperate, compromise and relinquish control.</td>
<td>Active and equal participation of 2 or more individuals. Interactions “characterized by respectful mutuality, power sharing, participatory decision-making, which requires relinquishment of professional power, collaboration and negotiation.”</td>
<td>Awareness of increased autonomy. Power control, Self-efficacy, Higher self-esteem, Self-determination, Greater satisfaction, Improved self-concept, Healthy behaviors promoted, Physical health and quality of life improve, Hope enhanced, Greater sense of inter connectedness, Expanding consciousness, Harmony</td>
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<td>Tyree, E. (2005). <em>Community empowerment for health</em>. Unpublished manuscript, Loyola University – Chicago.</td>
<td>Community</td>
<td>AGENCY: surrogate terms for agency include: “self-hood, motivation, will, purposiveness, intentionality, choice, initiative, freedom and creativity” (Emirbayer and Mische, 1998, p.962). Hope: based on a belief that something will come about, the desire for the future occurrence, and mental-imaging of the proposition (Bovens, 1999). PARTICIPATION: reaching the hard to reach may be the most valuable contribution of community participation. (Levin 1992).</td>
<td>SOCIAL CAPITAL: trust, social networks and participation, enhanced by “redundant contacts” which maximize the number of face-to-face encounters. Small groups are better than large groups for developing listening and trust (Putnam &amp; Feldstein, 2003). ASSETS-BASED CAPACITY-BUILDING: a focus on wellness rather than illness, competence vs. deficits and strength vs. weakness (Perkins &amp; Zimmerman, 1995). COLLABORATIVE PLANNING: including reciprocity and dialectical development (Freire, 1987; Levin, 1992).</td>
<td>PLURALISM: methods of healing and remedies consistent with the culture (Levin,1992). EXISTENCE OF ORGANIZATIONAL COALITIONS: “...participation with others to achieve goals, efforts to gain access to resources, and some critical understandings of the sociopolitical environment” (Perkins &amp; Zimmerman, 1995, p. 3). TRANSFORMATION: movement from social service to social justice (Himmelman, 1996).</td>
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"Community empowerment" gained importance to the discipline of health education in the late 1980's and early 1990's (Laverack, 2001). Ronald Labonte (1990), currently of the Saskatchewan Population Health and Research Unit, University of Saskatchewan, described a continuum of community empowerment process as: (a) individual empowerment, (b) small groups, (c) community organization, (d) partnerships, and (e) political action. "Community empowerment," "community development" and "community capacity building" were identified by Gibbon, Labonte, and Laverack (2002) as surrogate terms which describe "a process that increases the assets and attributes which a community is able to draw upon in order to improve their lives (including, but not restricted to their health)" (p. 485). Laverack and Labonte (2000) defined community empowerment as "the means by which people experience more control over decisions that influence their health and lives" (p. 255).

Glenn Laverack (2001), Health Education Advisor for the United Nations International Children’s Emergency Fund (UNICEF) in Hanoi, Vietnam, summarized organizational aspects, or "domains," of empowerment as: (a) participation, (b) leadership, (c) organizational structures, (d) problem assessment, (e) resource mobilization, (f) asking “why,” (g) links with other people and organizations, (h) the role of outside agents, (i) program management, and (j) implications for community development.

Nina Wallerstein (2002), associate professor at the University of New Mexico School of Medicine, summarized community empowerment theory as "processes and
structural outcomes related to participation, control and critical awareness” (p. 75), and identified empowerment as an intermediate outcome in efforts to improve health outcomes of populations. Wallerstein traced the origin of interest in community empowerment to studies demonstrating the effect of powerlessness on health. “Empowerment” had both horizontal and vertical dimensions. Social capital described the horizontal dimension of trust, reciprocity and civic engagement. The vertical dimension involved challenging those with “power over” the oppressed.

Labonte (2004) cautioned against employing “romantic localism” in considering communities of disadvantaged people, who simply sought inclusion in the economic privileges of mass society. Labonte advanced “social inclusion” as a more helpful concept than “social cohesion,” which he attributed to moral philosophy, or “social capital,” which he considered too vaguely encompassing of social variables of trust, reciprocity, participation and social network density. Social inclusion/exclusion represented the phenomenon, which created the condition of disadvantage to Labonte. Social inclusion stands for participation in community and society, while social exclusion removes the opportunity to do so. People are poor because they lack benefits, and people lack benefits because they are poor. Changing the fundamental power structures of the state was necessary to promote inclusion, and this could not be done without conflict.

Lay Health Workers

Booker, Robinson, Kay, Gutierrez Najera and Stewart (1997) studied changes in empowerment of lay migrant farm worker Camp Health Aids (CHA’s). Their open-ended interview questionnaire was administered at three points in time, shortly after the
aids entered the program but before training, four to eight months after training, and 16 months after the program began. CHAs considered to be low on the five point empowerment scale at two and three on the scale, had greater vagueness about life goals on entering the program, a narrower sense of the scope of farm workers’ health problems, and little identification with the larger community. CHAs identified at four on the scale had a broader view of farm worker health problems and a greater sense of control over their lives. CHAs in the range of five on the scale had goals, motivation and the desire to help others. The researchers concluded that level of personal empowerment at hiring was less important than the desire to help others. The benefits of empowerment for these workers individually and the provision of culturally sensitive care exceeded the improved access to care which they provided.

Hecker (1997) studied aboriginal health workers in Australia using participatory action research. The research question was what factors prevented aboriginal health workers from having a key role in their health service. The low standard of training, lack of literacy skills, and lack of inclusion in planning and decision-making were identified as the leading factors preventing the Aboriginal workers from influencing the health service. Consistent standards of training, greater frequency of training and more trainers were recommended as necessary to improve the Aboriginal workers’ performance.

In “Resources Revisited: Salutogenesis from a Lay Perspective,” Cowley and Billings (1999), working in the United Kingdom, recommended treating health as a process “fuelled by the accumulation and use of ‘resources for health’” (p. 994). “Salutogenesis” is a word invented to parallel pathogenesis, meaning creation of health.
In their grounded field study of lay health workers, Cowley and Billings observed that resources for health appeared "infinitely variable, being potentially internalized, individual and personal, or external to the person but arising from the situation in which they lived" (p. 995). Health resources were not limited to consumer items or financial means. On the personal level health resources included emotional well-being, physical stamina, and cognitive ability. External resources included extended family, and cultural influences, besides formally provided services. Cowley and Billings' study demonstrated interventions by lay health workers on all levels of the system, including the family and neighborhood, organizations, and formal provider systems.

"Salutogenesis" was derived from the work of Antonovsky (1987) who defined health as a sense of coherence. Manageability, comprehensibility and meaningfulness are integral to a sense of coherence. Manageability describes the extent to which people feel they have the resources to meet their day-to-day needs. Comprehensibility refers to the sense people make of their situation. Meaningfulness relates to the ability to fully participate in events which shape one's life. Salutogenesis may be seen to be operating on individual, group and community levels. The idea is to not limit the category of health resources to those identified by professionals, but to consider the life of a community in total and health in the terms of the residents.

Empowerment as Developmental Process

Kieffer (1984) theorized empowerment as a developmental process of a multidimensional participatory competence. The stages of development included: (a) the "era of entry," (b) the "era of advancement," (c) the "era of incorporation," and (d) the
"era of commitment." The era of entry consisted not of consciousness-raising or education, but of the perception of the "physical violation of the sense of integrity," an emotional or symbolic affront (pp. 18-19). Participation in this stage was tentative and unsure. The era of advancement was facilitated by a mentoring relationship, supportive peers within some organizational structure, and the "critical understanding of social and political relations" (pp. 20-21). Critical awareness and the capacity for strategic action were the developmental tasks of this stage. In the era of incorporation, participants confronted "institutional barriers to self-determination" (p. 22). Significant maturity in the skills of organizing and leadership developed, leading to a reappraisal of self as a political actor. The era of commitment was the "fully realized participatory competence," in which participants sought ways of exercising their new skills and insights (p. 24).

Two overarching developmental themes emerged from Kieffer's (1984) phenomenological study of fifteen adults involved in widely varying "grassroots' organizations. The first was an ongoing, internal "constructive dialogue" (p. 25), or cognitive dissonance, commonly known as "gut reactions." Conflict and growth were intertwined in this process. The second theme was a "circular relationship of experience and reflection" (p. 26), or praxis. Theorizing about empowerment was of no interest to the participants in Kieffer's study. This reinforced the critical nature of the development, in that participants sought avenues of action as the result of their experiences of conflict and their thinking about it. Kieffer concluded that empowerment was the result of long-term effort, or time; and required many opportunities to practice skills in reflective
experience. The role of an outside enabler or mentor was of primary importance to the participants as they struggled through their individual and collective development.

Summary

Previous studies of culture care among American Indians, individuals, and communities and the empowerment of these three groups provide a background for this study. Beginning efforts to theorize empowerment have been made by Kieffer (1984), Laverack and Wallerstein (2001), Persily and Hildebrandt (2003), and Labonte (2003). Contributions of this study to theory development on empowerment may be limited, considering Kieffer's finding that research subjects are more interested in action than theorizing about empowerment. Greater potential exists for contribution to the theory of culture care as a result of this study.
CHAPTER THREE
METHODS

Ethnonursing Method

This is a participatory action research study informed by the ethnonursing research method of Madeleine Leininger (1997). The ethnonursing method employs "enablers" as strategies of data collection. Leininger's priority was discovering generic care and integrating it into professional nursing practice. Her "Sunrise Model" (Appendix A) graphically displays elements of generic and professional care patterns with principles and interventions to guide nursing, which are: (a) cultural care preservation and maintenance, (b) cultural care accommodation/negotiation, and (c) cultural care repatterning/restructuring.

The primary constructs of Leininger's theory of Culture Care Diversity and Universality (1991) are "care" as the essence of nursing and "culture" as the totality of a human groups' values, beliefs and life ways. Leininger and McFarland (2002) term nurses' substantive background knowledge of care and culture as "holding knowledge." The ethnonursing research method involves discovering "human care and caring expressions, values, patterns, symbols and practices of culture" (Leininger & McFarland, 2002, p. 10).

Hunches

Participatory action research and the ethnonursing method require the researcher to be explicit about and reflect on the developing knowledge base. The author's "holding
knowledge” and the ethnohistory of American Indians of the Northern Plains lead to certain hunches. One hunch is that paradox is present in transformation of negative experiences. Many episodes of trauma resulted in depopulation and loss of some cultural anchors, either permanently or temporarily. Trauma continues to this day with high rates of domestic violence, suicide, and chronic illness compared to the general population. While trauma has been experienced as a constant, resiliency has also grown. Culture pain is experienced by American Indians, and has contributed to the development of strength in adversity. Poverty is rampant and not ameliorated so far by the entry of Northern Plains tribes into the entertainment business with the development of casinos. In the midst of deprivation, emphasis is on the well being of the community more than the individual.

Meaning is embedded in story and story-telling is a major communicative method among American Indians. Tribes are different in culture and history, even if geographically proximate. American Indian time orientation is different than that of whites. The CHR role has required study of etic perspectives on health. Empowerment is an intrinsic quality, and not a gift from outsiders. Based on CHRs’ knowledge of etic and emic perspectives, the question is whether CHRs know how to apply information from both paradigms in improving the health of their communities, and are thus empowered.

*Enablers*

*Stranger to Trusted Friend Enabler.* This study is based on ten years of service by the UND Nursing Center in training CHRs and consultation in grant writing. Trust
has developed as the result of loyalty of the UND Nursing Center personnel to the CHRs and their mission. Requests to broker entry to the reservations by other programs or professionals have been referred directly to the CHRs. The only linkage to outside agencies brokered by UND Nursing Center personnel has been in the context of applying for funding. Funding received has been administered by the Nursing Center for training, and by the tribes for health services.

Observation-Participation-Reflection Enabler. The Observation-Participation-Reflection Enabler (Leininger & McFarland, 2002) is an ongoing process. Prior to approaching the subject as a research interest, participant observer activities have been the source of the development of holding knowledge, since site visits made to all of the North Dakota reservation areas by the researcher beginning in October, 1990. There have been at least four visits to each reservation since that time for a variety of reasons, including a parent-child needs assessment, meetings, a powwow, visits to museums, and other outdoor recreation.

Acculturation Health Care Assessment Enabler. The Acculturation Health Care Assessment Enabler (Leininger & McFarland, 2002) was helpful in differentiating emic and etic perspectives, since CHRs have knowledge from both traditional and professional systems of care. Individual CHRs represent varying levels of acculturation in traditional or mainstream cultures. Individual interviews gave examples of appearance and clothing, worldview, spiritual beliefs and values, educational values, political context, folk care, professional care, caring concepts and patterns, and views of prevention. Detail was less accessible in estimates of technology available in the home, general social interactions,
patterned daily activities, some family life ways, economic factors, and home environment. Having general informants who are Native and non-Native enhanced estimates of acculturation.

Sunrise Model Enabler. The Sunrise Model Enabler (Leininger, 2004) provided a framework of concepts and observables, which guided the research during all phases (Appendix A). The Sunrise Model was used to identify specific characteristics of CHRs associated with traditional and professional care, and led to implications for nursing. Entry to the model in this study was at the interplay of generic or folk systems and the professional systems. Consistent with estimates of application of the Acculturation Health Care Assessment, observations of the environmental context, language, ethnology, religious and philosophical, political and legal, and educational factors contributing to cultural values and life ways and worldview were more accessible than technological and economic factors.

Orientational Definitions

Leininger and McFarland (2002) use orientational definitions, which they consider pertinent to qualitative research, rather than operational definitions, which are used in quantitative research. For the purpose of this analysis:

1. “Care” refers to “those assistive, supportive, enabling, and facilitative culturally based ways to help people in a compassionate, respectful, and appropriate way to improve a human condition or lifeway or to help people face illnesses, death or disability” (Leininger & McFarland, 2002, p. 11).
2. "Culture" is the “learned and shared beliefs, values and lifeways of a designated or particular group that are generally transmitted intergenerationally and influence one’s thinking and action modes” (Leininger & McFarland, 2002, p. 9).

3. "Culture care" has been defined as the cognitively learned and transmitted professional and indigenous folk values, beliefs, and patterned lifeways that are used to assist, facilitate, or enable another individual or group to maintain their well being or health or to improve a human condition or lifeway (Leininger & McFarland, 2002, p. 57).


5. Professional care, or “etic”, is care learned by nurses prepared in schools of nursing and practiced in professional contexts. Professional care includes practitioners of other disciplines, such as physicians and dieticians (modified from Leininger & McFarland, 2002, p. 84).

6. “Culture Care Preservation and/or Maintenance” refers to those assistive, supportive, facilitative, or enabling professional and generic actions and decisions that help people of a designated culture to retain and/or maintain meaningful care values and lifeways for their well-being, to recover from illness, or to deal with handicaps or dying (modified from Leininger & McFarland, 2002, p. 84).
7. "Culture Care Accommodation and/or Negotiation" refers to those assistive, supportive, facilitative, or enabling creative professional and generic actions and decisions that help people of a designated culture (or subculture) to adapt to or negotiate with others for meaningful, beneficial, and congruent health outcomes (modified from Leininger & McFarland, 2002, p. 84).

8. "Culture Care Repatterning and/or Restructuring" refers to the assistive, supportive, facilitative, or enabling professional and generic actions and decisions that help clients and professionals reorder, change, or modify their lifeways for new, different, and beneficial health care outcomes (modified from Leininger & McFarland, 2002, p.84).

9. "Empowerment," as defined by Rappaport (1987), is "a mechanism by which people, organizations and communities gain mastery over their affairs" (p. 122).

10. "Community empowerment for health" is an inter-subjective, assets-based, multi-level process and outcome of local, context-embedded group effort to identify and prioritize health problems and remedies, and develop health as a resource for everyday life (Tyree, 2005, p .68).

11. "Empowerment as a principle of primary health care" is demonstrated in the achievement of the other principles of PHC, namely, access to services, focus on prevention, appropriate technology and a multi-sectoral approach (WHO, 1978).
12. **Organizational domains of empowerment** are: (a) participation, (b) leadership, (c) organizational structures, (d) problem assessment, (e) resource mobilization, (f) asking “why,” (g) links with other people and organizations, (h) the role of outside agents, (i) program management, and (j) implications for community development (Laverack, 2001).

**Potential Biases**

My own potential biases had to be “bracketed” insofar as they influenced analysis. I worked with a cultural group, which has experienced poverty to the degree of destitution. Further, their history of subjugation, depopulation, and cultural imposition is real and compelling. While I do not assume personal guilt for the past, I bear personal responsibility for addressing systemic and structural factors, which perpetuate destitution in the present. My challenge was to avoid a victim-persecutor-rescuer dynamic coming out of my own life experiences. Cultural violence is possible among people who have suffered to the extent, which Northern Plains Indians have at the hands of others. Fear of reprisal and fear of getting it all wrong can be operating in me. Guarding against a kind of omnipotent fantasy that I could change circumstances, I reminded myself; I cannot be all-knowing, all-loving, and all-healing. In fact, I may be quite blind.

Also to be bracketed was the author’s interest in focusing on the relevance of the findings of the study to community empowerment for health. Empowerment is a lens through which to view the culture care values, beliefs and practices observed. The process is one of discovering what the people say about culture care first, and examining
that with the lens of empowerment second. The CHRs’ terms for demonstrating whether or how empowerment was present were key to the inquiry.

*Key and General Informants*

The key informants for this study were 15 past participants in UND Nursing Center sponsored CHR trainings from one Sioux reservation of the Northern Plains (Leininger, 2002). General informants were 11 Native and non-Native trainers, and elders. Characteristics of key and general informants are presented in Tables 2 and 3.

### Table 2. Ethnodemographics of Key Informants

<table>
<thead>
<tr>
<th>PARTICIPANT</th>
<th>AGE</th>
<th>SEX</th>
<th>YEARS AS CHR</th>
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<td>Key 3</td>
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<td>6</td>
<td>SRST</td>
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<tr>
<td>Key 4</td>
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<td>Male</td>
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<td>SRST</td>
</tr>
<tr>
<td>Key 5</td>
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<td>Female</td>
<td>6</td>
<td>SRST</td>
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<tr>
<td>Key 6</td>
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<td>10</td>
<td>SRST</td>
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<td>Key 7</td>
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<td>Female</td>
<td>5</td>
<td>SRST</td>
</tr>
<tr>
<td>Key 8</td>
<td>38</td>
<td>Female</td>
<td>8</td>
<td>SRST</td>
</tr>
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<td>Key 9</td>
<td>57</td>
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<td>23</td>
<td>SRST</td>
</tr>
<tr>
<td>Key 10</td>
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<td>Key 12</td>
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<td>Key 13</td>
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<td>8</td>
<td>SRST</td>
</tr>
<tr>
<td>Key 14</td>
<td>33</td>
<td>Female</td>
<td>5</td>
<td>SRST</td>
</tr>
<tr>
<td>Key 15</td>
<td>37</td>
<td>Male</td>
<td>5</td>
<td>SRST</td>
</tr>
</tbody>
</table>
Table 3. Ethnodemographics of General Informants

<table>
<thead>
<tr>
<th>PARTICIPANT</th>
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<th>SEX</th>
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<th>TRIBE</th>
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<tr>
<td>General 1</td>
<td>53</td>
<td>Female</td>
<td>9 Years</td>
<td>Wasichu</td>
</tr>
<tr>
<td>General 2</td>
<td>53</td>
<td>Female</td>
<td>9 Years</td>
<td>Wasichu</td>
</tr>
<tr>
<td>General 3</td>
<td>37</td>
<td>Female</td>
<td>1</td>
<td>SRST</td>
</tr>
<tr>
<td>General 4</td>
<td>65</td>
<td>Female</td>
<td>3</td>
<td>Turtle Mountain Chippewa</td>
</tr>
<tr>
<td>General 5</td>
<td>49</td>
<td>Female</td>
<td>3</td>
<td>Wasichu</td>
</tr>
<tr>
<td>General 6</td>
<td>42</td>
<td>Female</td>
<td>4</td>
<td>Spirit Lake Sioux Tribe</td>
</tr>
<tr>
<td>General 7</td>
<td>71</td>
<td>Female</td>
<td>NA</td>
<td>SRST</td>
</tr>
<tr>
<td>General 8</td>
<td>79</td>
<td>Female</td>
<td>NA</td>
<td>SRST</td>
</tr>
<tr>
<td>General 9</td>
<td>75</td>
<td>Female</td>
<td>NA</td>
<td>Dacotah and Hidatsa</td>
</tr>
<tr>
<td>General 10</td>
<td>73</td>
<td>Female</td>
<td>NA</td>
<td>SRST</td>
</tr>
<tr>
<td>General 11</td>
<td>57</td>
<td>Female</td>
<td>NA</td>
<td>SRST</td>
</tr>
</tbody>
</table>

Selection Criteria and Sampling

Employees of one reservation who received CHR training through the UND Nursing Center were invited to participate. Of the 14 CHR participants, 12 currently work as CHRs, and two were previously employed as CHRs, but now hold other positions as outreach workers. Experience as a CHR ranged from 1.5 to 23 years. Pseudonyms were used to protect the identities of the professional and indigenous...
participants in transcripts. Participant identities will remain confidential. Field notes were kept on content and tone while interviewing CHRs as a group and individually.

Data Collection

Talking Circle. Initial data collection occurred with CHRs in a “talking circle.” The talking circle is a traditional American Indian group process method (Struthers, Hodge, Geishirt-Cantrell, & De Cora, 2003). It is congruent with oral tradition and storytelling as a way of sharing information and making decisions. It involves participants seated in a circle and speaking in their turn in a round robin sequence. The role of a facilitator is to create a comfortable environment, exhort confidential treatment of personal sharing and promote safety. A talking circle is often initiated with a prayer. There is no discussion however there may be reference to a previous speaker’s comments. Participants usually listen and respect the individual who is speaking with full attention.

The talking circle has been adopted as a primary method in UND Nursing Center CHR trainings. The talking circle often follows an educational presentation and involves profound reflection on the content of the education. Tribal elders often participate in the talking circles with CHRs as “wisdom keepers’ who can reflect on how the “old ways” can help promote the health of the people. CHRs participated in two talking circles of about two and a half hours in length focused on CHR role development, one of which included elders. The planning and implementation of the talking circles was a collaborative effort between the researcher and Mr. Eagle Shield with the appropriate amenity of food available before, during and after the events. In the talking circle
convention, it is understood that everyone brings something to the circle and everyone takes something away from the circle. There is a focus for the talking circle and questions are provided. Mr. Eagle Shield provided the questions for the first talking circle, which involved the CHRs and the researcher:

1. How long have you been a CHR?
2. Why did you go into this work?
3. What is the most important thing you do?
4. How do you describe your work to people?
5. How do you think other community members see your work?
6. What do you wish people knew about CHRs?
7. If a visitor came to try to understand your program where would you take them on a tour?
8. If you described yourself in your role as a CHR in the form of an animal, a four legged or one that lives in the water or flies - which would you choose?
9. If the CHR Program in general could be described as an animal or insect’s home what would it be?
10. What or who has positively impacted your approach to your work?
11. How do you think (diabetes has affected) your community?
12. How has diabetes affected your work? Has it changed since you started?
13. What has been the most challenging part of your work among people with diabetes?
14. If you could tell people one thing to protect your health, what would it be?
15. What do you think your community could do to prevent diabetes?

16. Is there anything I haven't asked that you wish I had asked?

The researcher provided questions for the second talking circle which included five elders:

1. What lead up to development of the CHR (community health representative) role?

2. Are there Native traditions that keep people healthy?

3. What kind of traditional methods do people use?

4. Is there a connection between traditional methods and Western medicine?

5. Are there ways Western medicine should change?

6. Are there Native practices that should change because of information from Western medicine?

7. How can CHRs talk to people about changing their ways?

The talking circles were tape-recorded. Participants were asked to sign a consent form for confidential use of the audiotapes, which were transcribed with names changed to protect identities. Field notes related to the talking circles were recorded after the sessions.

*Individual Interviews.* Information from the talking circles was used as a basis to develop subsequent individual interviews of CHRs. The interview guide is presented in Table 4. Interviews ranged from one half to one and a half hours in length. Interviews were individual except for two female CHRs who chose to participate together. Data
collection with CHRs and elders extended over three days. The interviews with trainers extended over approximately six weeks and involved visits to two other reservations, plus
Table 4. Group and/or Individual Interview Guide

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Key Questions</th>
<th>Group and/or Individual Interview Probe Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What influences do worldview, ethnohistory, and religious and philosophical</td>
<td>How did the role of the CHR develop in your community?</td>
<td>Tell me about the kinds of things that led to the development of the CHR role? What things or events in your community have influenced the development of this role? How has your relationship with your community changed as a result of your role? Tell me about your role in the community.</td>
</tr>
<tr>
<td>factors have on culture care practices of community health representatives?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. In what generic care practices do community health representatives engage?</td>
<td>What is the CHR emic perspective?</td>
<td>CHR’s walk in two worlds, the western medical and the traditional Native worlds. Tell me about Native traditions that you think help people be healthy? What kinds of traditional healing methods do you see people use? Are people generally supportive of using traditional ways?</td>
</tr>
<tr>
<td>3. In what professional care practices do community health representatives engage?</td>
<td>What is the CHR etic perspective?</td>
<td>Some people tell me there is a connection between some traditional healing ways and western medicine. Tell me about that. Do you think other people see a connection between Native ways and western medicine? When people talk to you about this, what do they say?</td>
</tr>
</tbody>
</table>
Table 4 Continued.

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Key Questions</th>
<th>Group and/or Individual Interview Probe Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. What are the values and beliefs of American Indian community health representatives with respect to generic and professional nursing care and practice?</td>
<td>What can be learned from CHRs regarding “Transcultural Care Decisions and Actions” (Leininger &amp; McFarland, 2002)</td>
<td>Can you tell me ways that western medicine should change? Have your views on Native tradition or western medicine changed over time? Why? Tell me about traditional practices that you have changed, because of something you’ve learned about western medicine.</td>
</tr>
<tr>
<td>5. What culture care values, beliefs, and practices described by community health representatives indicate the presence of empowerment?</td>
<td>Do CHR’s feel hope for the future? What does “participation” mean in Indian communities? Is there a sense of agency or ability to influence events among CHR? How are social networks used by CHR?</td>
<td>Why would you want someone to change their ways? How would you speak to someone about changing their ways? How would you speak with them, or what would you tell them? How would you support someone who wanted to manage their health without using any western medicine? Under what circumstances do you think they should change or not change?</td>
</tr>
</tbody>
</table>
Table 4 Continued.

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Key Questions</th>
<th>Group and/or Individual Interview Probe Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there trust between and among CHRs?</td>
<td>Upon what community assets can CHRs build in their development of health?</td>
<td>I have heard that (insert relevant statements from talking circle or research notes leading to evidence for empowerment). Tell me how you see that.</td>
</tr>
<tr>
<td>What partnerships do CHRs have with other providers, agencies or services?</td>
<td></td>
<td>When CHRs talk about (insert relevant statements from group interview or research notes leading to evidence for empowerment), what do they say?</td>
</tr>
</tbody>
</table>

one telephone interview. Field notes were recorded of conversations with key and general informants, and visits to the reservation site. Additional materials collected included journal reflections of the researcher, a manuscript draft, UND Nursing Center project files, and newspaper clippings.

Qualitative criteria for the scientific trustworthiness of ethnonursing research can be demonstrated (Leininger & McFarland, 2002). Credibility is enhanced by use of direct quotations of American Indian CHRs. Confirmability is present in the maintenance of the original transcripts and the verification of the findings by an American Indian CHR consultant. Meaning in-context reflects
interpretation of findings consistent with the CHRs' worldview in their own environment. Recurrent patterns are identified which reflect consistent lifeways of CHRs and people of the tribe. Data gathering and confirmation of findings extended until saturation was reached. Transferability can be addressed by comparison with other research involving American Indians.

**Analysis of Data**

Leininger (1991, p.95) described four phases of ethnonursing analysis related to the phenomenon of culture care patterns. The first phase involved collecting, describing and documenting raw data by field journal and computer. Beginning interpretations were made in phase one. The second phase focused on identification and categorization of emic and etic descriptors and components. Extraction of meaning began here. The third phase included discovery of saturation of ideas and patterns of meaning. Meanings-in-context were identified and findings confirmed. The fourth phase is the highest phase of analysis, synthesis and interpretation. Themes, findings, recommendations and contributions to theory were identified in phase four.

The transcripts were read through twice and notes made in margins on content and tone. Preliminary categories emerged from the reading. Color-coding was done with markers on the transcripts according to approximately 16 emerging categories. The transcripts were then cut and sorted by the general categories. Each step of the data collection and analysis processes included reflection on the meaning of the information in the context of the whole data set in an iterative manner. The resultant themes and patterns are described with supporting quotations.
Ethical Review of Participatory Action Research

Approval of research with human subjects was obtained from the University of North Dakota and Loyola University Chicago, Lakeshore Campus. The Khanlou and Peter (2005) guidelines for review of participatory action research were used in preparation for Institutional Review Board reviews. The work with CHRs was undertaken in response to their direct request for assistance in reducing the high rate of complications of diabetes among American Indian people (See Evolution of the Effort). Identification and diagnosis of the problem on which action was taken was done by CHRs. A plan to train CHRs as “Tribal Diabetes Educators” was developed between UND Nursing Center personnel and American Indians.

Scientific validity is ensured through congruity with participatory action and ethnonursing research methods (Israel, Eng, Schulz, & Parker, 2005; Leininger & McFarland, 2002). Tribal support for the research was obtained through a Tribal Council resolution, and approval by the Health Committee and CHR director. All current CHRs at the respective reservation, who had participated in UND Nursing Center training, had the opportunity to participate and did. Confidentiality in the management of the transcripts will continue to be maintained. Minimal risk in participating in-group and/or individual interviews occurred. The benefit of the CHRs’ reflections on their ability to prevent complications of diabetes outweighed any risk associated with participation in the study. Informed consent was obtained from participants. No penalty was attached to a choice not to participate. American Indian people participated in the collection of data,
analysis of data, the draft of results, and the reporting of results (Freeman, 2005). No reports or publications issued from the data without approval by the reservation partners.

**Summary**

This study is based on ten years of work by personnel of the University of North Dakota Nursing Center with American Indian community health representatives in the Aberdeen Area Indian Health Service. The work was undertaken as a service without a research agenda. Efforts to date are consistent with the participatory action research approach. The research questions revolve around culture care values, beliefs and practices indicative of empowerment. The study is based on the ethnonursing research method of Madeleine Leininger. The heuristic value of the study is identification of generic and professional care patterns which may lead to: (a) cultural care preservation and maintenance, (b) cultural care accommodation/negotiation, and (c) cultural care repatterning/restructuring (Leininger & McFarland, 2002).
CHAPTER FOUR
DATA ANALYSIS AND FINDINGS

Findings emerged from observation, participation, talking circles and interviews. The process of extracting meaning from the data involved jotting down recurrent topics and collapsing these into categories. Themes were discerned through the contemplative process of “dwelling with the data.” Coding and classifying data required at least five thorough readings of the transcripts. Upon completion of the analysis, confirmation was sought from two Native and non-Native consultants. The term *Wasichu* was introduced to designate non-Natives.

The research questions were:

1. What influences do worldview, ethnohistory, and religious and philosophical factors have on culture care practices of community health representatives?
2. In what generic care practices do community health representatives engage?
3. In what professional care practices do community health representatives engage?
4. What are the values and beliefs of American Indian community health representatives with respect to generic and professional nursing care and practice?
5. What culture care values, beliefs, and practices described by community health representatives indicate the presence of empowerment?
Themes

Theme One – Poverty, Kinship and Spirituality

Poverty, kinship issues and spiritual beliefs influence CHR practice.

Pattern 1. CHRs vary intra-culturally in worldview and religious beliefs. All of the CHR participants are members of the same tribe and cultural group of that tribe. Nonetheless, they vary in their identification with the Indian traditions of the group. The continuum of variation includes strong adherents to Indian ceremonies and beliefs on one end of the continuum to confirmed believers in Christian religious practices on the other end of the continuum. A common factor among Indian people is belief in the efficacy of prayer. Two people remark on this; first, Indian perspective, …

For many years I’ve been participating and believing in the way our ancestors have. They taught us through song and they taught us many ways how to live. Our people [ancestors] are praying people...were praying people. They prayed for us. Now it’s our turn to do what we could for future people.

… and second, Christian perspective:

I didn’t know how to react to that [an infant death], but I tried to stay as calm, because I was brought up to pray a lot, to really believe on Jesus… But as a Community Health Representative, and also believing in praying, I try to encourage the clients that lost their loved ones, you know, to just sit and pray with them and just sit there with them...not talk or nothing.

The practice of Indian ceremonies by CHRs varies also. As Ken said, “I guess we’re talking about some traditional healing methods that really aren’t any secret.” The traditional rituals may not be secret, but they are sacred. It is beyond the purview of this study and researcher to describe or discuss the ceremonies, and it would be considered irreverent to do so, as a naïve Wasichu. Rituals include the use of medicinal herbs, the vision quest, the Sun Dance, the sweat lodge, smudging, singing, and the “wiping the
tears” practice with individuals who are grieving. Other practices, such as drumming and dancing, carrying the Chanupa Pipe, beading, and use of the Lakota language also identify the degree of adherence to traditional folkways by individuals. While CHRs may disagree about the value of the practices, they consistently demonstrate respect for whatever spiritual path one chooses. “There’s a respect across the board for each others’ stuff,” according to Darla, a Wasichu trainer. Variation in the practice of ceremonies or rituals is demonstrated in the following comments:

Nina (Key) “...what the elderlies usually tell me [is] that they really didn’t depend on all this [Western] medicine and stuff. Most of them went with traditional medicine and all that.”

Ernest (Key) “I would like to think that there are Native traditions that are still keeping people healthy today. And I know they are. ... Right now we have a lady in our district who does a lot of her own growing of traditional medicines yet, salves and stuff like that. ... She’s within our district and every year for the past two years now she’s just had one extraordinary garden, and she’s always giving us new things, and actually had some salve that did help heal some condition that my son had.”

Michael (Key) “Geez, I really got a bad toothache and it’s causing me a big headache! She [Grandmother] was in pain [from a broken collar bone] and everything, but she started telling my mom in Indian that, that’s the traditional part of the medications. She was looking for a, told her where the bitterroot was. She said ‘here chew on that,’ she said. ‘That’ll fix your toothache.’ ... So I took it. Shoot, by the time I got home, I got out there and got home, my toothache was gone and my headache was gone...”

Harry (Key) “I’m not going against any other people that they’re not doing this, but these workshops that now have maybe depression, stress, and I always kind of feel not to good about going to them. I have to go sometimes and it doesn’t sit too well with me because I...I know and believe it in another way, and when I’m overloaded...overwhelmed, you go to a home visit, and you hear all the whoas and ‘What’s wrong with me?’ When I leave there, a little better in a way, I talk spiritually. When it gets too much for me, I know, personally, I go home and I have to take care of myself. I am a caretaker of what we call “Chanupa Pipe” and a few minutes there alone, I’m okay again. And it’s not going to these
professional’s offices...stress relievers or anything...so that was kind of my answer for that.”

Fran (Key) “I’m not a person that believes in what [Ken] believes in. My grandpa and my grandma, they danced Indian but it was just the dancing. They never did no fasting or standing on a hill or nothing. My brother, before he died, he used to tell me stuff...it’s not like that, you know, because he was about 76 years old when he died and he’s telling me they don’t do it that way. They never did it like that a long time ago. And he said, don’t combine cultural with religion. He said, ‘It’s different.’ Long time ago, it was a lot stricter than what the Bible says he said. ... So that’s how I was brought up. I don’t know. We don’t dance or nothing. My mom used to dance but not us. My grandfather was a Congregational minister.”

Kathy (Key) “I go to church now and then, and there’s not that much going to churches, and I said, ‘How does that priest supposed to know when they do your funeral. How is he supposed to know you? How does he know your personality? That’s hard for them.’ So people need to start. Yea, we are praying in different ways and stuff, but it would be nice for people to go to church.”

Carol (Key) “I don’t really know any of the traditions from long ago, but I know that our life is much better these days.”

Betty (Elder) “My mother-in-law, I was wishing I had learned from her. She used to go around picking up the Indian herbs, those Indian medicines. She would work hard to pick. I wish, I really wish I knew.”

Sherry (Key) “In fact, to this day, my daughter alone (my 15 year old daughter) can speak the Native language. I can’t. So somewhere in between, it was lost between me and my mother. ... I really changed my life for my children, for my child to have a better life. So...I’m really surprised. I’m very proud to say that I am... I have raised her in the traditional values. She Indian-dances, jingle dresses. She carries the title of Junior Miss. So a lot of things have changed.”

There are similarities between Lakota and Catholic rituals. Smudging is a cleansing ritual with smoke, much as Catholics use incense for purification. The flesh piercing in the Sun Dance echoes the crucifixion. Christians say grace before meals. Traditional Natives thank the plant or animal, which sacrificed its life to become food.
Respect for that animal or plant, which had to die so that one could eat, is a reason not to over eat.

Some CHRs do not articulate elements of Native culture, which they see contributing to health. Sherry gives an example of this tacit experience of culture:

I never thought of it, but I have sweet grass and sage in every room [for smudging]. And I have this really pretty pine scent I use when I burn it. And I have bitterroot. I guess that’s unique. I never thought of it.

Regarding individuals’ identification with Native beliefs, Ken describes:

I think you’ll find that in the majority of houses, they may not speak the language fluently. They may not follow the traditions regularly. But in their house there’s spirit feathers, there’s herbs that they use, there’s sweetgrass, there’s sage, even though they don’t use them all the time, when in most difficulties, that’s the first thing they go for. They’ll take a little piece of sage, they’ll light it, the aroma goes out, and like I said in the majority of the houses here that’s what happens. They may not be active and everything, but when their most difficult time comes, they go back to that.

Returning to the Catholic analogy, lighting a candle in a time of trouble is common and similar to burning sweetgrass.

When asked whether Native traditions or rituals should change for the sake of health, the Wasichu trainers affirm the value of Native culture:

Laura (Wasichu Trainer) “We’d be better if we could go back to some of the… Even though I’m not an expert in their culture but the whole US has changed as far as we’re more sedentary. Family structures have changed over the years and this is just nation wide. … It’s kind of hard to go back to the way things were, but there may be some parts of that that would be nice for people nation-wide to have.”

Ellen (Wasichu Trainer) “I don’t know of any. I think consistently with health in almost every dimension, I don’t know all the ceremonies and it’s not my place to learn them, but what I know is very consistent with health, and probably they do come up to a place of oneness with understanding about our Creator.”
Darla (Wasichu Trainer) “...some of the very worst things that Western civilization has to offer, they have really embraced. So I wouldn’t say that they should change their culture. They should maybe look at the culture and see what it gives them and maybe shun more of our culture, because a lot of the things they’ve brought in from our culture has made them sick and there’s been the embrace of it.”

Native trainers supported the efficacy of traditional methods along side Western medicine, particularly consultation with a Native medicine person, the sweat lodge and smudging.

Rose (Native Trainer) “Oh, yes...yes I do. I think a lot of our elders right now are kind of practicing that. Like...we still have ceremonies and, so yeah, we do do that together ... that stuff... they take the medicine plus we still practice the ... you know, doing the sweat lodges and purification and all of that stuff. ...Each tribe kind of has a medicine man that works with the community, so if they could kind of pull in that person from that community with the patient and talk to him and you know ... they had both the traditional healer come from their reservation and then the doctor did his part with the medicines and stuff.”

Brenda (Native Trainer) “We actually, our facility just participated in a smudge, just a couple of days ago because we had a lot of deaths and when that happens, you know you smudge to keep spirits away, bad spirits away. To help heal and there’s a lot of prayer with it, a lot of prayer with that, too. There’s a lot of smudging that occurs.”

The role of a Native medicine person in health promotion and disease prevention is one which can be complementary to Western medicine. Nora is a respected elder who previously worked in the state psychiatric hospital. She collaborated with representatives of all of the North Dakota tribes and elders to identify the necessary qualifications of a medicine person to work in the state hospital:

We said whoever presented themselves, was it a lifelong learning process? Because now in today’s world, you hear some of the people who come from other reservations. This one who has been here on Standing Rock and can help with the suicide problem we had a few years ago. When he was four and five years old, [he was] working with his grandfather. So then he had lifelong learning. The family knew that. And this can be men or women. The second was said well, did
he learn from someone or she learn from someone? So then we have to, you know, we weren’t just primitive people who just jump on something and build something. People have to be qualified. So who did they learn from? And who did that person learn from? Was it somebody who learned it from a book, maybe, reading a book? And the next one is, Is it in the language? Remember when you look at a doctor’s prescription, I don’t know if it’s still like that, I haven’t had one. But the doctor’s prescription is written in another language. What they learned from. They have to learn it in our language. Nobody can sit there and do it in the Wasichu language. And remember the medical people are supposed to have taken an oath of Hippocrates they call it. They’re supposed to help people. And of course it doesn’t work that way with Western medicine anymore. They all, yeah, we’ll have to put out the money. But the other criteria is with or without payment. They had to use their abilities to help people.

While worldview, beliefs and traditional practices may vary among the CHRs who are from the same cultural group, their traditional values are consistently espoused and proclaimed. This is demonstrated in Theme Two, Pattern 1.

Pattern 2. Traditional family roles and relationships have been disrupted in the historical suppression of Indian culture.

Kinship is an important traditional relationship among the Standing Rock Sioux Tribe. In order to illustrate that kinship issues are problematic at present, it is necessary to describe the traditional patterns of family roles and relationships. To begin, a semantic difference exists in calling people “elders” or “elderlies.” There are many elderlies, but few elders. Both groups should teach the young and pass on wisdom. Elders are a select few that stand out as recognized leaders and are consulted about decisions and developments on the reservation, which affect all of the people. The importance of elders and elderly to the population and tribal government is illustrated by Ken:

We do not have enough elderly. It just seems like, you know, there’s, what is it, 450 elderly or those 60 and older on Standing Rock. So, they’re elderly, but even amongst that group, it’s a very small percentage that are elders that have some good strong wisdoms that they could pass on. … where some of our communities
still maintain a good deal of traditional following, a meeting doesn’t start until your elderlies are there. And even if you’re an elected official and you’re at the meeting, it still doesn’t start until your community leaders, your elderlies are there…. If everybody was there, it wouldn’t happen until the oldest person would say ok, we can begin now and then they would start the meeting.

Besides needing elders and elderlies playing their part, a proper response by youth is needed, according to Ken:

So, we’re trying to bring back at least this one cultural strength, this foundation of who your relatives are. And address them as such, as that promotes your acceptance and then you can start telling them, as relatives should. And we see this happening. The other part of it was because of relationships, whether it was formal bloodline relationships or just informal acquaintance type, there was a formality about it. If I was a youth and I found, or somebody was talking to me, I would either address them as Uncle, or Grandfather, whether they’re related or not. That was a show or a sign of respect. And we would listen to that person.

There’s still that cultural awareness of relatives, this whole kinship issue is known… But any other place you get up and you introduce yourself and all of a sudden that places you. People know, the elderlies especially will know who your family was and your relatives, and on back and on back. So, your acceptance is there. And each one of my staff has that. So that’s a benefit to the program. So, they’re accepted and all the training that they have, when they start speaking, they’re accepted on that side too… Probably, in my opinion, the biggest one [cultural strength] is kinship issues, even with the children that we have, and then with the elderly that we have now, is knowing who belongs to you… So, we always find new relatives here. Once you know your relatives, it’s not like talking to a stranger anymore.

In the sense Ken is conveying, “knowing who belongs to you,” means people for whom you have responsibility. This is a relationship beyond “to whom you belong,” if that connotes who will take care of you.

The ethnohistory of the group reveals that Federal policy, which suppressed Indian culture, disrupted traditional roles and relationships. During the 1930s, 1940s and 1950s many people were “relocated” to urban areas, and many came under the influence of alcohol. Children were sent to boarding schools. Ken uses terms such as the “lost
generations,” “disenfranchised,” and a “defeated” people to describe the individuals who “never received a cultural foundation.” As he says:

It may be our traditional ceremonies. It may be education. It may be just general awareness. Kind of lost out... And the CHRs that were, that came about in the 60's had to account for all of that. So, they were everything to, I guess, because it was needed. They really enabled our people. So much to the point that we still have that where everybody says, “that’s your job, to take care of me. That’s what you get paid to do.” So, we’re fighting that issue where people need to start to take ownership of their problem.

The manifestation of this loss of culture in families is described by the CHRs:

Wilma (Key) “The younger kids don’t really... I guess it depends on the family and how the family is set up, you know, if they really listen to the grandparents or... because...I don’t know...I’ve seen a lot of...some of the elderly that should be elderly, are drinking instead of...and so the youth are not listening to them because they’re drinking...”

Kathy (Key) “I think mostly [its] the middle-aged that want you to do everything for them. And we can’t. They need to help themselves. We could help them help themselves... A lot of things are happening. People are breaking in homes, these elderly homes. I see it first of the month because they know the pensions come in, or their Social Security... I’ve heard elderly gentlemen say they’re slapped in the middle of the night. They get up and here there will be about 3 or 4 of them, ‘Give me your money.’”

Carol (Key) “We’re really losing the family value. We don’t appreciate each other as much as we should.”

Michael (Key) [Responding to suicide attempts] “We sit there and bandage them up or whatever...and wait for the ambulance to come and then, you know, I just have the parents ask them to go stand outside, and talk to the kid. And the majority of time, it’s the parents...parents making them stay home and baby-sit, parents getting mad at them because they won’t baby-sit, and it’s just the littlest thing when it hurts the kid a lot...the teenager a lot...”

Nancy (Elder) “We heard that for years. For the elderly part, there’s a lot of abuse going on too. We see that in our community you know. Some of them, most of them are related and the elders won’t come out and tell you. They’re scared. ‘You want to sign this, or you want to come to a meeting when we talk about,’ ‘No, I don’t want to go.’”
Darla (Wasichu Trainer) “There’s the grandmas now who are almost in several levels, they’re some really young grandmas in their thirties and they don’t know they’re part of the lost generation or direct descendents of the generation that got lost.”

Ken (Key) “And now there’s another group of those young elderly that are coming up and for some reason, you pass the magical age of 60 and you have the right to complain, as opposed to these other elderlies over here who are always teachers. And then of course we have an even third one, who are young but they’re already grandmothers. We associate grandmas with elderly and they’re all wise in teaching. So it’s kind of confusing.”

When family members do not fulfill traditional roles and relationships, CHRs are often placed in the role of family. This happens on the levels of CHRs as elderlies in relation to youth, and CHRs as children in relation to elderlies.

Kathy (Key) “A lot of them [elderly] are alone. I always say, like CHRs, sometimes it’s maybe like a half hour, to hour, hour and a half sometimes, if nobody’s been around. You have to take that time to spend with them. Give them reassurance that someone’s here.”

Wilma (Key) “Because they know, you know, if you got family that can help you, you know, you got to have family that cares about you and this is [a] family thing. No matter what it is.”

Sherry (Key) “I don’t know, you become one of their family members when you go out to their family and to their homes. After a while, they trust you so much that pretty soon they address you as ‘my CHR,’ so when they do call the office, they’re like, ‘Where’s my CHR?’ you know, they get used to you and you’re probably the only ones that can see their feet and you are probably only the ones that can really address [their feet] too. On the reservation, we run a lot into like elderly abuse, verbally abuse.”

Nina (Key) “Well, I think we do really need CHRs just because there are some elderly people that really, really depend on us and they really look up to us…and for every little thing like they call you for this, for this….this one elderly in my district that’s lonely all the time and when she needs like…I mean, to me it’s like she wants attention. She will call me and I’ll go over there and she says I’m dizzy and I take her blood pressure and sit there and talk with her and then she’s okay. She’s talking and laughing and I think she just likes somebody to go and check on her all the time and then she does have a lot of family but they never check on her until something happens to her, and then they are all there and they want to
'CHR...CHR...how's she doing now?' I think most of them really depend on us...CHRs.”

Ken (Key) “We used to say that, not to be callous or anything, we have a group of elderly now who are sick, who have ailments and in the years to come just won’t be there. So, we can support them, make them comfortable now but in essence our concentration is our youth. They need to have all the latest health information. They need to have all the latest social information. They need to have all the cultural information. So, when they become of age, they will know how to be responsible. And that is a tremendous job. And it really isn’t our responsibility. That has to do with families. But again you can’t help but getting involved.”

Hope stems from raising children with a cultural foundation who can restore the traditional kinship relationships.

It is necessary to balance descriptions of negative behaviors with a reaffirmation of the cultural strengths of the CHRs and the tribe in order to avoid harm to the community. There is a reality about the problems described, but it is also necessary to avoid over-generalizing about family dysfunction, or conveying that what is happening on the reservation is different from the experience of other elements of United States society. There is no intention to blame the victim for social problems. CHRs confront these challenges on a daily basis and doing so constitutes a major part of their work.

A recent phenomenon is the entry of former CHRs into the ranks of the elderly. Two of the elders who participated in the second Talking Circle had been CHRs 30 years ago. The benefits of that are that they understand the CHR role and the toll it takes on the individual, and they have basic health information, which they continue to share with neighbors. As Ken reflected, “I always like to think that my staff are the young elders.” Three of the current CHRs had parents who were CHRs. As Susan said, “Well, my dad was a CHR and people would come to the house, you know, I’d seen arms cut open and
blood going all over the house.” Growing up witnessing a parent being called out at all
hours, and the physical trauma that is part of the CHR job as a first responder, a son or
daughter knows what they are getting into, when they decide to do the job. Ken
observed, “It’s like what Nora was talking about when they were trying to find criteria
how to recognize legitimate medicine people. And one of that was family involvement,
life-long teachings.” CHR work has taken on a multi-generational aspect similar to that
of traditional medicine people.

**Pattern 3.** Byproducts of poverty include multiple tragic developments and
events.

Most of the CHRs described their childhood as growing up without modern
conveniences. The CHRs recognize the value of that lifestyle in encouraging exercise,
preventing over eating and limiting access to sugared drinks.

Wilma (Key) “because I lived with my grandmother and that’s how we lived too,
with chopping wood and hauling water from a pump and the kerosene lamp and
all this and we never...never over ate. It was a treat to go out once...just once
you know and to even have a bottle of pop was a treat, you know.”

But those circumstances are not entirely a thing of the past:

Sherry (Key) “We go into molded houses. We go into people that don’t have
heat. To this day, can you believe that we still have people on our reservation that
don’t have any running water, that don’t have no electricity,...or they are using an
outhouse It’s out there and, you know, we’re out there to try and do the best we
can do with what we have...”

Darla asked one of the CHRs what she does on a home visit and was surprised to hear,

“Well, I go take the buckets down to the river and get her water.”

The poverty the CHRs see today seems more pernicious than what they
experienced.
Sherry (Key) “I think what we really fight against too is our poverty line, our income. A lot of us can’t shop for the fresh vegetables and the fresh fruit and all this. A lot of our people are on food stamps, on commodities, and that’s all they got to work with.”

Brenda (Native Trainer) “I think a lot of the problems that we encounter now are the poverty problems. The alcoholism, the drug use, that’s a big problem. When you’re trying to get through to a patient and there’s, there are those factors. The poverty being that certain times of the month some people may not have food to eat, they may be feeding their kids before they themselves have eaten, therefore not taking their medication properly and for the CHR trying to tell them that’s really important to take the medications, or even a provider to tell them that.

Darla (Wasichu Trainer) “The whole social dynamic and all the difficulties that people have. They really can be traced to poverty. Some of the horrible tragedies that happen, they’re tied up with poverty. Even something like kids are committing suicide. Why is that? And where’s the escape into drugs coming from, and how many people are committing suicide under the influence of drugs? Nobody knows that. Nobody knows how much that’s all tied together. It’s really an unknown.”

The CHR Program has formed partnerships with a number of aid organizations, such as the American Indian Relief Council, which provides Thanksgiving turkeys.

Several “nongovernmental” voluntary organizations provide goods and services to the reservation sporadically. The impact of the influx of donations on the CHR Program is that CHRs manage the storage and dispersal of the donations, which is physically taxing and time consuming. Potatoes, squash, corn, peaches and watermelon were scheduled to be dispensed to elderlies during the week of the Talking Circle. A few years ago the television program, “Wild Kingdom,” sent veterinarians to neuter and spay stray dogs on the reservation that were becoming a hazard to anyone on foot. In fact, dogs killed one woman, on a bicycle. CHRs helped staff the dog round-up. In the past, they have also participated in a mass euthanasia of 450 stray dogs. That was a counter-cultural act,
since the tribe valued dogs in days past. The dog problem must be considered in advising diabetics to exercise by walking.

The CHRs recognize the value of physical work in preventing diabetes and other chronic illnesses. They observe different practices among people today:

Wilma (Key) “But, a lot of the families are set in their ways and it’s such a small community and a lot of them don’t work. I don’t know what it is, but it’s like they don’t care, you know. It’s like if it happens to them, you know, if they’re older or they’re overweight, it’s going to happen to someone else…not to me. So, I’ve been trying to, you know, work with the different families and I mainly…the women is the one that I work with a lot…that listen to me a lot more. And that’s what I usually share with them, you know, with what I went through.”

Nancy (Elder) “You see it with your own eyes, drugs. Some of the elderlies from the other districts, they have to lock their doors to keep safe, they’re keeping their grandchildren. Most of them are taking care of their grandchildren, because their mothers, dads are out there doing things like that.”

Besides changes in lifestyles, changes in attitudes have occurred. Fatalism, anxiety, depression and negativity influence many:

Ken (Key) “I don’t know if you thought about this, but when it came to diabetes, it was pre-ordained, it was destiny. And I still come across individuals that say, ‘Well, When I get my diabetes, I’m gonna do this.’ Even those with diabetes, I know some amputees who say, ‘When I get my other leg cut off, you know, I’m gonna do this and this.’ And believe or not, we know people who created their own diabetes. We know individuals who say, ‘here drink this pop and drink that.’ They have hopes of getting on disability and not having to work and all these kind of things.”

Fran (Key) “Just before I left this morning I got a call from one of the districts and they were concerned about this man that’s on disability and that’s not taking care of his health. He’s a diabetic and he’s not taking his insulin. His leg is just swollen, so what can they do. I didn’t know what to say, so I said, ‘could you go to the tribal court and sign a complaint on him that he’s not taking care of himself? And maybe that will make him come back to clinic.’ She said, ‘He hasn’t been taking his insulin for about a month and his leg is pretty well swollen. He barely can get his pants leg over it.’ I just talked to the prosecutor and explained to her what this lady told me. I said I referred her to you. I don’t know what else to do. He’s not listening to the family members. He’s not listening to
nobody. What can we do? I wanted to go down and see what. Those are the things we deal with.”

Nancy (Elder) “When I go to clinic and see mostly all young people sitting there seeing the doctors. And I wonder, I’m sitting here wondering, am I the oldest one sitting here? But there’s other, older ones coming in for their appointments. But it’s getting back with the younger, it seems like they don’t care. They don’t care what’s happening to them, because nobody cares out there, is what they say. Nobody knows. Then they start using those cuss words, ‘give a damn about us.’ ‘Who cares,’ you know. Or go out and get drunk. And they heard about one of my grandsons saying that.”

Darla (Wasichu Trainer) “And then somewhere the dysfunction comes in, even with those moms and grandmas and, I don’t know, if domestic violence used to be a Lakota thing. Or have they absorbed that? But if you watch enough of our stupid movies, if you get broken away from your family early enough, so you don’t know how a man’s supposed to act, and you have the poverty and the whole issues of no employment and all that stuff. I doubt that there was probably a lot of that going on back there.

Diseases, substance abuse, violence or threat of violence take their toll on the population and contribute to other problems, such as unintentional injury, automobile accidents and the high rate of suicide among the youth. The roads are winding and unlit at night. It may not be known whether a particular car crash is the result of suicide, drinking, hypoglycemia, or some other cause. CHRs tend to their community members who are experiencing the full panoply of the results of poverty. They demonstrate strength in doing so, but cannot escape the consequences of poverty in their own families. The question of how CHRs persevere is addressed in Theme Two.

**Theme Two – Inner Strength**

CHRs perform multifaceted jobs with inner strength and positive outlook, but at some cost to themselves.
Pattern 1. The values of respect, generosity, fortitude, courage, humor and humility guide CHRs in their dedication to their people and work.

The value most often repeated by the CHRs and observed by the trainers is respect. Respect for elders and elderlies is primary and grandmothers rule.

Brenda (Native Trainer) “I would say they utilize a lot of our values, values that are taught to us, you know, when we’re growing up. First of all, with the respect that they show to the elders. That’s a priority with anything for them.”

Darla (Wasichu Trainer) “Even though it may not always be carried out because of some particular dysfunction going on in the family, but it is still a claimed value in the culture, to respect elders and care for them and to listen to them. So even if you don’t agree with them, you’re to listen to what they’re saying and that is ingrained... I think the respect for elders ties into the whole pathways of how people used to live, and they were active.”

Nancy is a particularly active elder who attends as many Tribal Council meetings as she can. She is a conduit for information to other elderlies:

Well, I hope that us as elderlies, you know we can give help. I know we like to chew out our kids some times. You know, “you’re doing it the wrong way.” But nowadays the kids, like I have a son on the Council now. He thinks he knows everything. Him and I get to argue with. Get’s mad right away. He’s right. “Oh no you’re not. We’re right. You better start listening instead of telling us what to do. You better start listening, you want to stay on the Council.” We get into it that way. Again he kind of apologizes. He calls me, “Mom, you need some money?” or, “You need some money for gas?” He knows I was mad so he’s trying to apologize.

The grandmothers know the traditional path to health and communicate a value for being robust:

Ellen (Wasichu Trainer) “They would talk about breastfeeding and about how much support women need for that... And then they talk about early feeding and that was something I hadn’t really thought about. They’d give instruction about introducing babies early to the vegetables and things like that and teaching them that those were good. And then just being active and robust and being grateful for the chance to be that way. And mixed in there, spiritual sacredness about the gift of hard work and good food ...”
One elder told Ellen the story of collecting beans from little mounds where you reached in and got the beans, but you left something for the mouse that put them there, again with respect and thanksgiving. The grandmother participants expressed hope in the return to tradition by younger generations during the Talking Circle, and offered to consult with those who worked with youth.

The CHRs have internalized the traditional values of respect, generosity, fortitude, courage, humility and humor. As Darla observes:

If you don’t have those values, you don’t have a CHR program... They’re empowered through their job by those cultural values. If they weren’t there, they would not have the power to carry on every day, with all the setbacks, all the politics, all the getting called in the middle of the night, all the poverty they gotta deal with themselves. To have the fortitude to keep going. They gotta have the compassion that keeps giving with the guy that is never gonna stop drinking.

Their values are their source for perseverance in adversity. Several of the CHRs described attending horrific automobile crashes in their first week on the job. They questioned whether they could do the work. After much soul-searching, they continued in the role with certainty that they could make a difference. It is their longevity in their positions that demonstrates the values they espouse. They don’t do it for the money.

Brenda (Native Trainer) “They have a lot of passion, they love what they do, they care. They’re really persistent. They’re very funny. They are trustworthy. It’s just that the love of their job, they can leave and do something different, but many of them haven’t. They’ve stayed at the job for years and years and years.”

Kathy illustrates the courage of responding to late night calls:

Usually when it’s late at night or something I know it’s serious, I ask them to get the ambulance rolling my way anyway because it takes so long for them to come from Fort Yates or Wapkala. I got down there. They lived way in a creek. You had to go way back. I didn’t tell. Everybody was sleeping. My husband was sleeping. I didn’t tell them where I was going, but when I got down there this couple and another lady they were partying. And I looked at her. I got my gloves
on, went over and looked at her head. I was talking to her and I said, “Well, I
know for sure the way it looks it needs stitches. I’ll pack it, I’ll bandage it and
stuff till you get...” I asked her where she wanted to go and she said, “Mobridge,
it’s only ten miles from us.” I said “alright.” And here, I said, “what did you hit
your head on?” I was going as I was wrapping her head. And she looked at me,
she said, “I didn’t fall down. He clobbered me over the head with a board.”
Chills ran down my back all the way down and I stood there and I thought, “Oh,
my God, this was a domestic.” And I was right in the middle of it and he was
there. I said, so I kind of, I was scared myself and I said, “You know what? The
cop’s on the way and the ambulance so we best just meet them on the highway.”
I said to get out of that house. So she was coming and he didn’t say anything he
just let [us go]. I was scared of him but at the same time I was trying to be like I
was this authority. And we got out of there. I was so thankful that he let us go.

Humility is shown in the respectful manner in which CHRs talk about people. It
is rare that disparaging words are said. The most incriminating thing that is said may be,
“What goes around comes around.” Darla describes, “…they’ll often preface things with
things like, ‘Well, you know it’s not for me to say’ or ‘I wouldn’t do anything, I won’t
say anything about them because I have problems myself.’” Kathy reiterates, “The only
thing I could tell people is I myself am not above anybody. I’m not better than anybody.
I don’t proclaim to be and I always tell them, if there’s a better way...”

Humor is a mainstay as a value and coping mechanism:

Evelyn (Native Trainer) “Our tribe, we use a lot of humor, lots of humor. People
are always making jokes. Even when something is seriously going wrong, they
use humor to cover it up... It’s just; we use humor to cover up our feelings. And
I think the CHRs do it, because when they do tell their little stories, sometimes
they put just a little twist on it to make it humorous.

Humor is often expressed in the form of a story, which is told and retold. The following
vignettes were excerpted from the transcripts:

Ken (Key) “I told a story about Wilma yesterday [who was in the process of
starting a walking exercise group]. She had an odometer from the roads garage
and it measured how many yards, quarter miles, half mile. And she went all
around Little Eagle [Ken demonstrates Wilma hunched down rolling the
odometer]. She measured all the streets, the walking path, and when she was finished a couple hours later, the guy says, do you know the handle extends?"

A retired CHR had this encounter, described by Ken:

I always tell a story about Hal. He retired and he’s home enjoying himself. But he did a home visit one time and he came upon one of his relatives and he said, anyway, he came over to the house, the guy was sitting at the table and he said, “What’s the matter?” “They told me I have diabetes.” Hal got into his CHR role and started talking about diabetes, this disease is preventable, it’s controllable, … you can live a long time. Well, “And then he gave me this bottle and said, “I’m supposed to take this for the rest of my life.’” And he [Hal] started telling about the medicine, what it’s for, what it does, how it’s gonna help you after you eat, and all that. “I know, I know, but look, he only gave me thirty days to live.”

Ken cautioned the participants in the first Talking Circle about imparting cultural knowledge to youngsters:

I remember visiting one of the classrooms at Head Start and the teacher was talking about, “You know, the eagle, the Indians revered because it flies so high and it flies the longest … and all that.” And one of the kids says, “Na Nah. The grey Canada goose flies the highest and the longest.” And it’s true. The Canadian goose flies the highest and it goes across two continents. So you can’t really be talking about things like that in front of kids. “Na Nah, it’s the grey Canada goose.”

The initial planning meeting for Tribal Diabetes Educator training in 1997, was held on Holy Thursday during Holy Week. As Ken was getting ready to leave the College of Nursing for his six hour ride home, Darla said, “Well, Ken, you know, I hope this didn’t disturb your Holy Week observances.” And Ken says, “Oh, that’s okay. We’re so poor we just color our powdered eggs.” Some audiences hear that story literally and express compassion for such dire straits, but Ken was just kidding.

The CHRs may not always live their values, just as we don’t, but they are in touch with this part of their cultural heritage. They draw strength and camaraderie from their shared values. As Wasichu Trainer, Ellen, says, “It does permeate further than any of us
know, the goodness that they do.” The work also takes its toll on the CHRs as individuals.

**Pattern 2.** CHRs experience health problems, tragedies and stress similar to the population they serve.

The CHRs themselves and their families are not immune to the problems experienced by the larger reservation population. One difference is that as they work through problems and crises with their families, they still function as providers to others in need, as helping para-professionals. The cultural strengths bolster their work, and then the culture of poverty pulls them down. “You can’t just untangle yourself,” as Darla says, when your lights are turned off, or your pregnancy becomes complicated, or the most recent suicide is in your family. “But it’s really a stressful time at times, especially when those car accidents happen, especially when there’s a lot of alcoholism in our community,” says Kathy.

The CHRs are in agreement that the most difficult part of their work is in responding to automobile accidents, particularly when children are injured. One story, told by Sherry typifies the experience:

... here there was seven of them in the vehicle (five children, two adults) and none of the children had seatbelts, from probably three months to five years old. And, uh, we all responded. I always say that there was somebody looking after these people because ... I was a CHR, and later on what came up was two nurses. So we all responded ... and there was so many kids and adults that were really hurt that I remember holding one, I think she was like a four year old ... three or four year old ... in the back of the passenger seat there in the van. And I held her and here she was gurgling ... then I always thought well, if I didn’t tilt her head and hold her c-spine that, you know, she would have been gone. And when I did pull her to the side with her mouth, all that blood came out. So I just heard, and there was babies crying, and there was actually ... I couldn’t move because I already had took this spine and c-spined her and was holding her. There was
actually a baby that was in the car seat, but wasn’t strapped down, and she was lying on the other side. My first thought was, I wanted to let go and run over there, but there was nothing I could do until more nurses came. I think when I actually got to the hospital with all these kids, we sent two of them with passersby, the ones that were more basically stable; we sent them to the hospital, [we were] just 25 miles south of Fort Yates. We got them in and we waited for the other three ambulances to show up, and that was like a half hour wait. And this was just, you know, trying your best, and to work with what you have and having people, you know, take control of the traffic. I, everything pretty much went good, so when we got into the hospital, and I was sitting outside with my daughter, I just totally had a breakdown. It was too much … I think with the kids, when you see children hurt, it always stays with you. But, I got back and then I had cried and, you know, all this, but the CHR role is very important.

The officers of the North Dakota State Patrol receive critical incident debriefing following response to car crashes. There is not an equivalent mental health first aid for the CHRs and others who respond to accidents on the reservation.

Physical and/or mental illness in the CHRs themselves or family members contributes to stress.

Ernest (Key) “I’ve had a couple of heart attacks … it goes back to the genetics of it. I was just dealt the wrong card, but that’s what made me really change around and turn around, and find out, hey, you know, I need to start taking care of myself.”

Ken (Key) “…my second grandfather. He died just across the river here in Mobridge. He died over in the city jail. He died because they thought he was just another drunken Indian, but in reality, he was in a diabetic coma, so they hauled him off and he died.”

Wilma (Key) “You know, it’s easy for me to tell them this, until I became a diabetic, and then I was experiencing a lot of these problems, I guess with diabetes, and I seen it from a different view.”

Kathy (Key) “Right now our Dad’s really sick. He has cancer.”

Tess (Key) “I was 223 lbs when I was diagnosed with diabetes and now I’m down to 147 lbs. But last March, I lost my son [in a car crash], and when I lost my son, I got down to 130 … just not eating … just … I even went back into smoking … something I’d stayed away from for a few years.”

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Wilma (Key) “And, uh … we had a lot of suicides on the reservation … a lot from my district, and my daughter happened to be one of them … my daughter didn’t live with me anymore and she was 25 years old.”

Darla points out a paradox in the cultural strength of having a large, supportive extended family:

They’re resilient because of these family extensions, and all these people that are there to help them, and take care of them, extended family. But the paradox is they’re also weakened and die early because they’re so worn down from not taking care of just themselves, and getting an education, and moving on, and getting a good job, and living nice, because they’re going to stay there on the reservation and help everybody.

The difficulty results not so much from the fact that they as families experience the same hardships as families in mainstream culture. The stress results from repeated crises following fast on one another, which don’t allow a recovery period before the next crisis occurs.

Pattern 3. People in the communities CHRs serve have expectations for a wide variety of assistance from CHRs.

In the early days of the CHR Program, CHRs were committed to being on-call to their districts 24 hours a day, every day. If they left their districts, they had to find back-up coverage. The national CHR Program began in 1968, and CHRs had six weeks of training to do the job in the early days. The content included basic plumbing and car mechanic skills, among others. While those skills are no longer expected of CHRs, the majority of them describe their jobs as “jack of all trades.” Darla recounted one of her first encounters with Tess, a former CHR:

Tess at the time said, well, “I had to be up all night last night.” Well, what was that about? Well, they’re going to have a big chili feed for some big event.
...Someone showed up at her door in the evening with a hundred pounds of hamburger that needed to be made into chili. So she and her husband, she and her daughter fried hamburger all night, and got the chili ready for the next morning.

On another occasion Fran procured turkeys for every household of an elderly and all of the CHRs were detailed to deliver turkeys. Fran recounts:

...one time, I followed an elderly until midnight, because I had her turkey and potatoes. And I wanted to go home, but I knew that if I didn’t deliver those, they’ll be calling the next morning.... We don’t have the choice of picking out how many pounds of turkey they get. But I can remember one elderly got mad at me and she said, “I need a 30 pound turkey. This turkey is too small for us.” I mean, I thought, well that’s for you, not your whole family.

Darla’s perspective on the tasks delegated to CHRs which are not in their basic job description as health educators, is:

So they’re kind of jacks of all trades and also expected to be masters of several. I see them responding all the time to community needs and I don’t know if that’s a good thing all the time, because then you can never develop a focused health plan. If you’re everything to everybody at all times, but politically, if they don’t respond, there are calls made to leadership.

Transportation is a big issue among all of the tribes in the Aberdeen Area. In 1983, the number of CHR positions at Standing Rock was cut in half from 24 to 12, similar to the other tribes in the country. This was a change from about one CHR to 350 people, to one CHR to about 1,000 people. The on-call expectation ceased and the role evolved into mostly transporting people to appointments. Even if residents had an alternative source of transportation, CHRs were called to transport. Many stories are told of providing a ride to clinic and back home, and then meeting the individual at bingo. After transporting the person, the CHR would be expected to deliver the medication to the house, instead of the person waiting for the prescription to be filled at the clinic.
According to Ken, the job description, which hasn’t changed in 38 years, “says that we will provide health education, health information, training and skills so our people can participate in their own health maintenance. In other words, to help them to help themselves.” Ken illustrates his view of self-care with a story:

So they were talking about tribal sovereignty, and then, I think it was in the Little Eagle community. There was an elderly gentleman who had a garden, and so they asked him, “Well, what do you think about tribal sovereignty? What’s your definition?” And he said he looked at sovereignty as like he had his own garden, because he was independent, that was his sole responsibility. That was his sole endeavor and he was able to provide for a lot of older people. He said, “Before I even started, I had to prepare the ground. And then if I needed something I planted here. If I needed some more I planted here and here and here. And then I’d have to nourish it. I’d have to pull weeds. I’d have to take care of that. And then when I harvested it, it fed my family. It fed my relatives. It fed my friends.” So, when he looked at sovereignty, he said, “I always think about my garden.” And I was thinking about it in the same way with our health here. We need to think about this garden that’s in here. We need to start thinking about our own personal sovereignty. How do we become independent? How do we take care of ourselves, our needs? So we’ll be here when our relatives need us.

Curtailing transportation was necessary in order to implement the job description of health educator. In circumstances in which the person has no other transportation alternative, the CHRs still do transport or deliver medication refills. But the majority of their time has been redirected to home visits, work with youth and other activities. Each CHR has talents in particular areas, such as being a first responder trainer, and working with elderly males. The CHRs collaborate, crossing district boundary lines to help each other and share their skills.

Recently, each of the CHRs had been provided with a lap top computer and digital camera to enhance their service delivery and accountability. Up to the present time there has been no comprehensive baseline data on CHR activities. Without the
figures to demonstrate how many people have been served in what kind of activities, the CHR program is open to criticism from people who do not know what the CHRs do. The external funding, which provided for the office to be wired and equipped the CHRs with computers and cameras, is beginning to show results in the first collated CHR data summaries by individual CHR.

"Community Profiles" which identify the families in their districts with individuals with chronic illness are being completed by the CHRs. For the first time, in a systematic manner, people with chronic illness are being asked whether they want to be visited by CHRs and how often. This process has already been useful in responding to a complaint to the Tribal Council from someone who is not being visited. The CHR can document that the person declined services in her own handwriting.

The elders who participated in the Talking Circle also were aware that people complain sometimes about not knowing what the CHRs are doing. They exhorted the CHRs to work together among all of the health programs on the reservation. The CHRs find this has become more difficult since passage of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Between HIPAA and Homeland Security requirements, the CHRs have less access to information and less mobility. Doors are locked in the clinic, which were not in the past. They accompany patients into doctor appointments less. Diabetes Educator, Nettie, describes the CHRs as the link, which completes the circle of care, and believes HIPAA should not create a barrier to providing comprehensive, coordinated health services.
The CHRs know better than most people the conditions on the ground in their districts, the environmental issues, substance abuse problems, and the rate of chronic illness. They reflect on the frustration of helping one individual, but knowing there are many more in need. They are very sensitive to complaints about what they are or are not doing. Ken’s wish is, “I want everybody in CHR country to know that human beings with feelings are providing services.”

**Pattern 4.** CHRs meet problems, including tragedy, realistically, but turn toward the positive.

Ken asked the CHRs to think of stories, which illustrated their work, and to bring those into their interviews. When asked if they had thought of any stories, several of the CHRs responded that the stories are all too tragic, and they were reluctant to bring them up. As Ernest said, “So, for the most part, it would be I think probably the tragedies, you know, outweigh more than the ‘good times,’ for the lack of words.”

The CHRs have all experienced the tragedies. Fran recalled being called out to a home at 3:00 AM to find an eight-month-old infant, who died from someone, who had been drinking, laying on her. Wilma has a new connection with mothers who have lost children to suicide or car crashes since her daughter’s suicide. Darla described a CHR racing to bring a man in cardiac arrest to the hospital and stopping by the side of the road to do CPR, to no avail. One problem is that these are not similar to urban first responder calls. The people are relatives or relatives of friends. The community expectation is that the CHR will rescue. Some of the CHRs have arrived late to training because they have
been on a search and recovery operation. When a death is the result of a crime, the CHRs are the most effective at finding a body, because they know the area.

There are individual incidents, which are transformative for the CHR, and the person served.

Sherry (Key) “One story I wanted to tell you was about a suicide that I came upon. I was called out so I went out and here when I got out there, a police officer was actually cutting down this 18 year old boy. And what, it really affected me because I actually seen the person drop to the ground. He was actually hanging. The cop said, ‘don’t touch him, don’t touch him, stay away.’ And I argued with him. I said, ‘No, I’m a CHR. I know what to do.’ I said, ‘so you know, stay away.’ I told him to get away. So, if I didn’t open this eighteen year old boy’s airway, and had the knowledge that, what I knew, what I learned, this boy would never be alive. I did the chin thrust movement and here I got him to where he took a breath. His lips were blue, his eyes rolled back. And it’s sad because we always carry this with us and the good thing about it is this, that he did get treatment. He left to Bismarck. He went into the psych ward for 4 days. He left and he was gone for over about 8 months out of, you know, he was away from the reservation. So the happy thing is that he did get a job. He got a job and he was working on the reservation and now he has two, three kids, and at least we changed somebody’s life and we helped somebody. And that there alone is, it’s something to be happy about that. And I am very proud to be a CHR, helping wherever I can.”

The CHRs make a conscious choice to rise above the tragedies they encounter.

This is not a process of denial, but a decision to proceed with a positive attitude and hope.

Ernest (Key) “The biggest part is trying to keep this all positive. Of course, we have a lot of negative aspects of that, we come across, but to me I guess it goes in one ear and out the other … I’m not a negative person. Anything negative that comes to me, I try to turn it to the positive. So that’s where I’m at. It’s just the positivity that we have for the program.”

Kathy (Key) “What keeps me going is working with my elderly and trying to be a positive person. I’m not the best. I just can encourage them and try to encourage people to do the right thing… My Mother always says, ‘As long as you help somebody.’”

Sherry (Key) “All the sickness and stuff, you know, it don’t need to run with us. We can change and a lot of people are scared of change but it’s good… A lot of
things can be turned and a lot of things can be changed. We can do it ... well, we’ve been focusing on our elders, but what’s time for us to do, and we as CHRs know, is that we have to start educating our young.”

Michael (Key) “I like being there for people.”

Ellen (Wasichu Trainer) “maybe tying in the kind of community advocacy, fighting for your people kind of part that people know, because they have always risen to the occasion, when there was a threat against people. And come together to deal with this, because it involves the children’s health too.”

Darla (Wasichu Trainer) “I’ve asked people, how have you done that [handled an angry outburst]? ‘Well, they yell at you and everything, but they’re probably just having a bad day. So you go away for a while, and then you go back. And usually by then, then they’ll let you in, you know, it’s something else they’ve been worried about, and then you can have a good visit.’ Well, you know, I don’t know too many people can do that.”

There are photographs lining the halls in the Standing Rock Tribal Headquarters building of Lakota ancestors dating back to the arrival of photography on the reservation. This is the home of Sitting Bull and the current Tribal Chairman is a great-grandson of Sitting Bull. When the tragedies of the present moment seem ready to overwhelm emotion and consciousness, someone can always say, as Kathy did, “...if we think we have it so hard, we don’t. We don’t ... think about our ancestors what they went through. They were very strong and humble people and they prayed a lot.”

Theme Three – Improve Access

CHRs improve access to health care using scientific knowledge and skills and connect scarce medical resources to a population in need.

Pattern 1. CHRs play a major role in the management of chronic illness in the home and community.
The role of the Community Health Representative is variously described as an intermediary person between the hospital and the community, a liaison between the clinics and the community, a bridge, and the "in-between" people. The context of their work is a health care system, which lacks continuity of care. "Locums," temporary staff filling in for IHS vacancies, provide most the medical care.

Standing Rock has been known to have more than 300 locums in a year. Long term commitments by medical practitioners, nurse practitioners or physician assistants are rare. A nurse practitioner with over 30 years of experience at Standing Rock recently retired. A provider with that longevity can partner with a CHR to provide well-tuned case management services. Locums who rotate in short term placements of two or six weeks not only do not know the community, they may not know diabetes or other chronic illnesses well. Committed to being a liaison, a CHR may not actually connect with temporary medical staff. The next best option is for the CHR to have a relationship with a clinic staff member, such as the Diabetes Educator, Nettie, who recognizes what CHRs do and values their role.

Oftentimes, CHRs were unaware of chronic illnesses prior to special training, which began, in the mid to late 1990's. Tess tells the story of observing the "hospital car" picking up a neighbor every other day, not aware that the woman was being treated with dialysis, a procedure unknown to Tess. When Tess was called to the house, because the woman had trouble breathing, she could rely only on the woman's belief that she was having a hypoglycemic reaction and needed something sweet, such as Tess' banana. Fortunately, Tess began transporting the woman to the hospital before her diabetic coma.
worsened. “I didn’t understand any of it. It was new news for me,” Tess recalls. She went to the clinic pharmacist to learn about the connection of sugar to diabetes. Gradually, Tess associated the blindness and amputations she observed in her patients with diabetes, and began to see the disease affecting more and more people. “I didn’t want this for my people,” she said. Her view of diabetes is “You get possessed by something evil and it stays inside of you.”

Tess began attending workshops on diabetes. “I told them that I was there to learn about diabetes and I wanted to learn about diabetes from inside out.”

Tess (Key) “…during that time, we were just pulling them out right and left, … gosh, the number just shot forward … There was just so many undiagnosed, and so many that already became insulin dependent, when they were, you know, when they were discovered. And so, just during that time, our diabetes … all of a sudden the CHR program just went … just into that area … it took a few years before it actually slowed down…”

As Ken says, in 1995-1996, “we had 200 people that were diagnosed with diabetes…. Today, we have 1,275 people…. A vast majority of those were discovered by you, by CHRs in the screenings.”

Darla’s perspective, as a Wasichu trainer is, “…don’t dismiss CHRs and give them just rudimentary baby knowledge…. And so our trainings were pretty, might have gone over the heads of a lot of people, but some people sucked up as much as they could.” Having increased the rate of diagnosed diabetes in the population six-fold through screenings and public awareness, the CHRs had a new mission, which made providing unnecessary transportation pale by comparison.

Once the CHRs sprang into action on diabetes, they began identifying real needs, which people had on the community level.
Darla (Wasichu Trainer) “The other story that Tess told me was in the summer when people don’t have air conditioning, she had all these people who were dialysis patients and whatnot, and she set up her own home as a clinic with fans and water and keeping people cool. And she and her daughter cared for all these people who could sit around her house all day to be relieved of the heat because they couldn’t cope with the heat without air conditioning.”

Ken (Key) “Other times, we worked in blizzards. I remember three different blizzards. I remember one time where we got to the point where Tess called in, along with the other authorities, a National Guard helicopter to come and take dialysis patients…”

The main focus for CHR home visits is elderlies with chronic illness. Carol works to keep people, to whom she refers as “my elderlies,” in their homes and out of the nursing home because, “they would rather die at home instead of, you know, away.” Carol partners with families who provide substantial home care. Then she trouble shoots on clinic visits to see to it the person’s desire to remain at home is heeded. “It’s a struggle because, if they have breathing problems, they need 24-hour care. Then they have no choice but to go into the nursing home, because some of them need oxygen.” It has been on a rare occasion that a patient has oxygen in the home, because families are reluctant to manage it.

Darla (Wasichu Trainer) “I have now since identified their role as case managers for their elderlies, whether it be to get them to clinic, check on them for safety, see if they need groceries. Are their meds filled? Are they taking their meds? Just everything that needs to be done for an older person. They seem to be aware of and on top of. Then there’s the people with diabetes. These are the people with blood pressure problems, they’re taking blood pressures, they’re checking on them, they’re getting them to clinic.”

The model now is for CHRs to live in their districts and manage caseloads of elderlies and people with chronic illness. Transporting patients has been cut back significantly and CHRs themselves visit the central office in Fort Yates infrequently. The
expectation is that they will make five home visits in a morning. They are well informed about the health needs in their districts. Some have additional nurse aid certification. Next steps include obtaining reimbursement for their services and partnering with IHS providers to reduce barriers to health care. Frustrating as the shortage of physician or midlevel personnel is, the CHRs value the locums who do come. They just want more of them and more who stay.

**Pattern 2.** The correct use of prescription medication is a high priority in CHRs’ work with individuals.

Medication management can be multifaceted. The issues CHRs need to be aware of include: (a) interactions with traditional medicine; (b) an aversion by some people to Wasichu medicine; (c) unused or expired medications remaining in homes which can be confused with current medications; (d) timing and strength of doses; (e) side effects; and (f) a black market trade in prescription drugs. Currently, the problem solving related to medication issues exceeds the prior role of CHRs in what was basically a delivery service.

Stoicism is a common trait of the elderlies. As Sherry describes, “A long time ago, if you ever sit and listen to our people talk, our elderlies, is that they didn’t complain, they didn’t say ouches, they didn’t say ooohs, you know.” So, the CHR may not always have a willing historian in their attempt to help an elderly. The elderlies can be intimidated by a provider, get far less time than they need to feel comfortable in a clinic visit, and be reluctant to disclose use of herbal medicine. Elderlies do not necessarily value Wasichu medicine.
Rose (Native Trainer) “... a lot of traditional people don’t like to take their medicine because they see it as a foreign thing that they’re putting into their body, and so as a CHR worker we try to explain the physiological changes in the body and how the medicine will help them. ...but you can still use some of that other, your traditional way, and use the Western medicine to kind of balance yourself. And then I go back to that thinking, what my grandpa told me, that you kind of got to use both ... well, right now, you use it both ways to stay balanced.

As Nina says, “I think that the medical people, like the personnel, when the elderly or anybody goes to see them. I think they should really explain...” The communications are a two way street which often detours without the vigilant participation of the CHRs in plans of care. Evelyn, a Native trainer, believes change is needed on both sides. Evelyn believes a more concerted effort is needed to blend Native and Wasichu medicine, as she has seen in the Southwest. She also believes people need to shed some of the stoicism, “And so I think the clientele needs to change also because they could be helped more.”

All of the CHRs express a belief in the efficacy of Wasichu medicine. As Harry, who prefers Native ways says, “Yes. I do believe. I am more so [on] this other side, but I know medication, without it, a life shortens. I’ve seen it already.”

Reviewing what medications are or should be in the home, proper dosing and potential side effects can be managed by the CHRs effectively. Some medications need direct observation by the CHR of the patient taking it. The black market in pain pills is a complication, which has an impact on CHR work. The CHRs have to present a letter authorizing them to pick up medications, present their driver’s license, and have the medication count verified. Those interested in purchasing pain pills seem to know who is being treated for what and approach patients directly to purchase. The CHR role is to protect the interests of the patients and counteract the black market.
**Pattern 3.** CHRs motivate change in health practices among their clients by indirect methods.

Indirect approaches to patient teaching outweigh direct approaches. Kathy described an encounter with an inebriated man and his similarly impaired friends at a health fair. When she told him she would check his blood pressure when he sobered up and urged cutting back on his drinking, he tried to pin her down, “How much did you want me to cut back? A quart or a half a pint?” They had a fairly public encounter, which was exasperating for Kathy. Finally she said, “If you keep drinking like this, you’re either gonna have a stroke or heart attack.” Afterwards, Kathy continued to visit him with the same message. Eventually he did have a stroke, after which he sought her out and said, “I should have listened to you when you told me about my drinking and all that.” After the stroke he changed his behavior.

Kathy’s directness in telling the man to cut back on drinking is fairly uncharacteristic of CHR encounters with elderlies. As Nora says, “We have a very, very difficult thing to talk to someone about changing their ways.”

Darla (*Wasichu* Trainer) “I think that [advising behavior change] has been a challenge for them. Especially when it comes to respect for elders. I don’t even know if the CHRs would presume to correct an elder. So they’ll help them and they’ll do everything they’re supposed to do, but I don’t know if they would be directive to an elder. That might be a cultural barrier.

Brenda agrees that the CHRs would not tell an elder what to do, but in a very respectful way, would be “helping them to make the decision in a round about way. And I guess, I don’t know, they try to interpret or provide education in a way that they’ll, that anyone in our community, will understand.” Given the preponderance of indirect communication, it
has been a learning experience for the *Wasichus* to recognize a message when they hear it from the CHRs.

Ellen (*Wasichu* Trainer) “The way people teach. This has taken me toward the end of the ten years to realize that I was being instructed a lot more than I realized. That in such gentle, indirect, kind and loving ways, that I missed it early on.”

A message is often couched in a story. As Kathy says, “I kind of use stories with them, give them examples from your own life.... I’m not from there, but I always use my own family as examples.” One story she tells is that her parents raised 11 children, but they are not expected to baby-sit grandchildren. She uses this example to tell people that they need to be taking care of their own children. Kathy’s father has cancer and the plan is to take care of him at home. “We all take turns and we’re all gonna take turns when we bring him home. But that’s the way we are. I try to tell people it’s teamwork. It’s not just one family member doing all this and that.” And there are the humorous stories. Some time past her mother broke a rib, which necessitated her mother and father changing sides of the bed. Then on a Sunday, as the whole family was gathered for dinner and he had everyone’s attention, her father said, “I wish you’d hurry up and heal up, because I’m starting to have bingo dreams.”

The CHRs use several educational methods with people. Enlisting the grandmothers can be an effective way of getting the message out. Several CHRs have walking clubs. Michael’s goal is to certify a member of every household in CPR, and he has almost achieved it. Ernest employs experiential learning with youth:

...we brought them together and we had them help us make the sweat lodge by actually going out and picking the cherry tree, finding the right size tree, chopping it down and so forth, taking it and letting it dry out, and ... not really dry out, but
mend together and then dry out, and then actually having the sweat and having them participate in it; and then before that, the gathering of rocks, you know, the storytelling ... the storytelling that went on before that and just bringing them together and coming together and showing them a traditional way of, you know, this is how maybe generations before us was taught. And I think that aspect right there gives the kid a different perspective on life. You know, I think it will give you that perspective of, “Hey, I think I need to be more responsible in my decision making...”

One of the more creative events sponsored by CHRs at another reservation was at the local mall. The CHRs made a sheet cake, frosting and all, and Kool Aid with Splenda. Evelyn describes, “every time somebody took a bite of the cake or drank something, they [the CHRs] would all start singing.” As Kathy says, “CHRs have to walk the talk. We can’t be telling people to do other things, if we’re not doing them our self.”

On the population level, the CHRs have had success in moving candy and pop machines out of the waiting room at the hospital. Promoting increased water consumption by the people has been effective. A new weekly radio program featuring CHRs promises to be a vehicle for health messages. To an outsider one to one communications can seem circular and it is often only in retrospect that the message is understood.

**Pattern 4.** CHRs bridge Native and Western medicine practices.

One challenge of transcultural health care is linguistics. When the CHR program began in 1968, there were many more non-English-speaking people on the reservations. CHRs were vital in the medical care system as translators. Currently, there is less of a communication issue between Dakota, Lakota and English languages, than there is between Dakota, Lakota and English meanings. Brenda attributes part of the problem to the “time thing:”
I get that a lot that, "well I saw this specialist and he came and saw me for two minutes and he didn’t even hear what I had to say. He told me this, but that’s not what’s wrong. He didn’t hear me tell him." So, I think the time thing is really, I guess, the important factor in giving that extra ear.

Another issue may be the nature of Native and Western science. As Ellen says, “We’re not the ones who really know. The people who really know are the ones in communities who are living this every day and they’re doing science too.” Practitioners of Western medicine could acknowledge that they don’t have the corner on science. Native knowledge includes the values of generosity, gratitude for hard work, and being robust. Health is broader than just the physical. It’s the balance of mental, spiritual, emotional, and physical. Nora, a participating elder, questions how people in previous times avoided cataracts, incontinence and osteoporosis, major problems of the elderly today. “What did they do and how did they live? So we were talking about an old practice that we had. But you know, it’s different today, and this is why we can’t go into traditional practices.”

Evelyn’s perspective as a Diabetes Program Director is, “I feel like Western medicine should change. I don’t feel the client should feel afraid to tell their doctor that they’re doing this and the doctor should be more accepting of, yes, there is alternative medicine out there.” She cites Navajo programs in the Southwest which “intermix” Native and Western medicine. Ken agrees:

They should be able to recognize our cultural traditions, our persons who are practitioners of healing. The Indian Health Service has a line item for traditional healer, and they use it a lot in the Southwest, in New Mexico and Arizona. But they don’t treat the traditional healers like physicians and it’s not meant to be. But it’s complementary.
The practice of Native ceremonies has implications for people's health. Major accommodations of Western medicine have already been made in the ceremonies.

Brenda (Native Trainer) “I guess I would be a little cautious with, I know it’s, that Sundances are really sacred, and those are things that we don’t discuss much, but I know that there are potential risks for diabetics [in] that Sundance, because they fast, they do a lot of fasting, and some people don’t take meds at that time. So there’s potential there for hypoglycemic events. There’s potential for anyone who is offering a sacrifice of flesh offering for infection and if they’re diabetics, we’re worried about any infection and healing times and all of that. So, I guess I would be a little cautious with that. I’ve actually had someone talk to me about that and they were going to participate and they spoke to their leader and they advised them that, well, the Creator has somehow presented this medication to you to help you, so that’s ok that you do that, that you take that.”

It is a major Native accommodation to attribute a Wasichu medication to the Creator.

Fruit juice is allowed during the Sundance and blood glucose levels can be checked.

Participating in a sweat lodge has a different kind of risk.

Evelyn (Native Trainer) “And sweats are really very good because they get all the impurities out. But, he didn’t have any feeling in his feet. So he got too close to a hot rock and he burned his feet. It took us so long to get him back to where he should be. In that regard, I think the CHRs, if they know they’re going to a sweat, or if they know they’re going to do something, they need to remind them to do whatever they need to do to protect themself from different elements that you wouldn’t even think you have to do.”

If it has been only in the past ten years that the CHRs have developed sophisticated knowledge about diabetes, it is not unusual for their clients to know less than they do. Darla described a story she heard which illustrates the information base someone might have. Tess encountered a gentleman at a gas station who had a bandaged foot following the removal of a couple of toes. He told her, “I don’t know why this happened to me.” The man had been through the clinic and hospital and still didn’t understand that diabetes could cause him to lose toes. Tess, meanwhile, had to be
prepared to do diabetes education at a corner gas station. Similarly, Laura described a common scenario:

A lot of times they’re drinking those sweetened drinks to quench a thirst. They don’t realize that they have diabetes, until they get at the point where they have to come in and they have a very high blood sugar, and you’re questioning on what they’ve been drinking, and they’re drinking juices and pop and anything they can do to quench their thirst, and they’re not thinking that probably they should have gone to water or diet pop.

CHRs can be creative in advocating for clients. Sherry describes more than once sitting in the clinic waiting room. There is a sign in one clinic, which says, “if you have chest pain or aching, contact the front desk.”

Well, you know, they’re so quiet, and humble, and everything that the only way I noticed it is that they had a hard time breathing…. A couple times is that where I’ve took them (male elderly) into emergency back there, and I had to keep on buzzing the emergency door, and I did that for about a good 20 minutes and nobody came. So luckily, I went over to the police station, which is probably maybe 100 yards away, and I had them phone in. Well we got him in eventually but you see, we’re so understaffed over there…

CHRs have the knowledge and skills to bridge the gap between Native and Western medicine. The context of medical care in the IHS system limits direct access by the CHRs to consistent medical staff. Providing culturally relevant training to new providers about the people and the community is the ideal, but it is hardly feasible given that the system is under such stress and turnover is so high. Darla recommends, “If I had a goal that would be one thing; I would press for a little bit, that there be a whole lot more communication between providers and CHR programs directly.”

Theme Four – Health Promotion in Remote Areas

CHRs promote health in proximity to remote populations and through collaboration with other services.
Pattern 1. CHRs collaborate with other first responders in emergency calls.

The CHRs are most often the first ones on the scene in emergencies, and they take the first responder role very seriously. As Kathy says, “You called me out and I’m gonna check you regardless. But if you call me out, I come out. I don’t mess around. I take it serious, if you’re hurt or you call me.” The fact is they act with authority and people respect that. “Either you’re going in or..., especially if they’re intoxicated, you’re either going in by ambulance, or you’re going to go by the cop. Which one do you choose?”

There are several vacancies in the police force, mainly because people cannot serve in that capacity or carry a firearm, if they have a criminal record. Police have called Kathy to check on reported fights. She goes to the house and tells people to behave because the police are on their way. At other times people have come to her house:

“So and so took my money. Can you come down here and make them give my money back to me?” And I always think, “Who am I?” And we kind of got that authority, they think. And like, “you’re the CHR. They will believe you.” … There’s a great story, how do you say, actresses and actors. That’s what I always say. I’ll be listening to some of them when they’re talking to the police and stuff and the police will say, “What do you think?” I’ll say, “go ask the other ones too and kind of see what [the] story [is].”

Early in Nina’s CHR career she was called out to a shooting in the country. She attended to the victim until the ambulance came. “It just didn’t dawn upon me, you know, that I might get shot at too.” Other CHRs were following the situation on the police scanner worrying about her. Sherry describes this experience:

I always hear at night, at 3...4...5...o’clock in the morning. I hear my coworkers who work way outside of where there is no police, there is no ambulances, nothing. You hear them, you know, doing CPR. You are hearing them transporting at night. You are hearing them going out on calls.
The respect for the CHRs’ authority in emergency situations was illustrated at a United Tribes conference in the Bismarck Civic Center, when a pregnant woman fainted. A gentleman came running to Sherry calling, “CHR! CHR! There’s a lady down over here.” Sherry and her coworker calmly assessed the woman, as bystanders stared. The man who alerted Sherry declared, “Well, the CHRs are here. The CHRs are here. It’s going to be okay.” Sherry recalls, “After everything got over, and we stood on the outside, we started laughing about it because there was actually nurses and doctors there.”

CHRs have increasing knowledge, skills and equipment as time goes on. Most recently they acquired automated external defibrillators (AEDs) and five different sizes of blood pressure cuffs. They received a workshop in basic counseling skills to aid in their responses to individuals at risk of suicide and family members of trauma victims. Knowing an ambulance is on the way is small comfort in an emergency, given that it may be coming from 50 miles away. When the patient is elderly, they may not want to go with a non-Native ambulance crew, in which case they sign a waiver and may be risking serious consequences to their health. CHRs encourage Native emergency staff to stay on the job for this reason. The CHRs know the distances ambulances have to cover to any remote location. It is frustrating when the arrival time for the ambulance is beyond what they expect it to be. Worse, when it takes a long time, and the CHR is giving CPR for 30 or 40 minutes. At a time like that the CHR hopes for other equally committed first responders to take over. It is difficult if the relief personnel move slowly and call the death quickly.
CHRs embrace the role of first responder. As Michael says, “We’re out there … every community, and we’re the first ones to see what’s going on.” Sherry reiterates, “Though some of them, you know, we don’t know where we’re going into with the … sometimes alcohol and drugs. You know. You are the first responder. You are the one that has to do it.” And Fran confirms, “…that’s the job I enjoy doing, is helping other people in their time of need.”

**Pattern 2.** CHRs form partnerships with other services and programs.

The CHR Program at the Standing Rock Reservation is a “638” program, meaning it is funded by the Indian Health Service but administered by the Tribe pursuant to the Indian Self-Determination and Education Assistance Act of 1975 (Public Law 93-638). Therefore, the program is Tribally controlled and the employees are Tribal employees, not IHS. Some expectations of collaboration with IHS, such as in the provision of training to CHRs, have not been met. A fundamentally needed partnership between Tribal Health and IHS has some drawbacks. On the one hand, there is a feeling, a need, for closer collaboration with IHS. On the other hand, Ken says, “So whereas we couldn’t get trainings from Indian Health Service, this college would give us training. They’d even write the grants for us to get the funding to do this training.” The collaboration with the UND Nursing Center is an example of the partnerships Ken has formed.

One mechanism for forging partnerships within the reservation has been the health fairs, which CHRs sponsor. “…that’s why we put up those health fairs, so that the people in that district will know who to call on for different things that they need help
in.” The fairs can serve a two-fold purpose of connecting residents to services, and giving the programs the opportunity to communicate with each other. Clearly, the elders are looking for closer collaboration among programs. There is a concern about duplicating programs. The elders would like to understand what the programs are supposed to be doing, and they also want increased effort in home visiting and programming for elderly residents. Nancy reported asking at a meeting with the Tribal Chairman:

“What’s going on?” “There’s no funding.” I’m pretty sure you can get something done, if you get all these programs working together. That’s what they brought up yesterday. If we just get together and work together, we will get something done. That’s all we ask for.

Nora’s recommendation for the weekly CHR half hour on the radio is, “I think you [CHR]s need to repeat that over and over again, what the CHR Program does now.”

In fact, the CHRs collaborate with a wide variety of programs on the reservation. They are called upon to “track people down” by the Women, Infant and Children’s Nutrition Program, Suicide Prevention, the State Health Department, and to make mental health follow up calls. On a programmatic level they have connections with Tribal Council members, the Health Committee of the Council, local District Councils, IHS doctors and nurses, Bureau of Indian Affairs police, the ambulance service, school staff, public health nurses, the Diabetes Educator, North Dakota State Health and Human Services, American Indian Relief Council, The Centers for Disease Control and Prevention, UND Nursing Center, Sinte Gleshka University on the Rosebud Reservation and many others. Ken is a proponent of partnerships, “what I would like to see is to
develop a protocol where we all complement each other. We all become partners, and are recognized for the services or abilities that we have.”

In part, a missing link between the CHRs and IHS is symptomatic of the stress both programs are under, as they have less money and less people than they need to do the job. As Sherry sees it, “We need more people to work at HIS … our facility. They’re just too overwhelmed. So I can bring all this negative stuff about IHS, but you know, they’re the ones who are helping us.”

**Pattern 3.** CHRs experience a lack of recognition of their contributions to the health of communities served.

There is almost no literature on CHRs. Darla recalls an *IHS Provider* article in 1993, which described CHRs as “the vital link.” Recognition would bolster the CHR Program in several ways. First, individual CHRs could experience more appreciation for what they do. Ellen believes, “So they may have more respect than they realize, and maybe more potential to do more and be heard, because people know they care.” There is a burden of reciprocity on the *Wasichu* trainers to give back commensurate with the gift of learning and spiritual meaning the CHRs have shared with them. This research represents some of that reciprocity, telling the story in exchange for the beauty of the story. As of this time, the researcher has no evidence that an “honoring” of CHRs has occurred in a North Dakota tribe. This typically could occur at a powwow in the form of an honor dance, with or without a reciprocal give-away, the giving of gifts in thanksgiving for the honor. Undoubtedly, individual CHRs have been honored at memorials, which are held the year after a death, for their care of a family’s loved one.
Nationally, Ellen knows that there is great interest at the Centers for Disease Control and Prevention (CDC), in all of the chronic disease programs, for the potential CHRs, community health workers, and promoters have in the management of chronic disease on the community level. According to Ellen, who is employed at CDC, similar support for outreach workers exists at the American Medical Association and Surgeon General’s office. As she says, “It’s big.”

Ken is looking for another type of recognition. He has pursued training for the CHRs. He likens the preparation for the role through training to the old Morrell Meat Company slogan, “quality goes in before the name goes on.” That the CHRs periodically receive training raises some people’s eyebrows on the reservation.

People used to say, “My goodness, all the training you’ve got, you must be a doctor by now.” And they don’t understand that for us to give our best, we need to have the best. So, nowadays, even before the question comes up, I always tell people, “Well, I’ve got my CHRs in training. They’re gonna be a doctor, so they’ll be able to better help you.”

Credentials are an issue for Ken. In the past, CHRs received a paper certificate upon completing training workshops. For the last several years, the training has been run through Sitting Bull College, the local tribal college. Workshops are designed to meet the time and content requirements of the College, and the CHRs receive college credit for attending training. Ken believes the CHRs have cultural credibility because they are from the tribe. He also wants them to have academic credibility. As he tells the CHRs:

But now you need to be professional. You need to have the latest most accurate information, health information, so you can sit there and talk to them in terms that they will understand, and then, as you do your encounter form, you can turn that back to IHS and say this is what happened, and this will be part of their record.
Over time the CHRs have developed in health knowledge and skills far beyond the early
days of the program. They have that. Now they want recognition. “So that’s kind of the
difference I see from when I first came on 23 years ago, as the Great Enabler to the
people. Now, I’ve changed it around to be the empowering agent, the agent of change.”

**Pattern 4.** CHRs take a broad view of population health, identify new problems
to address and have insight regarding prevention of health problems.

CHRs recognize that many of the health problems they see are preventable. Darla
says, “They haven’t quite hit the prevention mode. They’re always in an intervention and
reaction mode. They’re not able to proactively do preventive education. They’re still
always having to a reactive thing.”

The necessity to focus on youth in nutrition education, physical exercise, and
most recently, mental health is generally recognized. When Ernest was chairman of his
district council, he and colleagues obtained funding for a $1.4 million dollar gymnasium.
Ernest had been away from the reservation for a while and observed the youth activities
available in mainstream culture. There are gymnasiums in other districts, which cannot
be open due to lack of funds for propane to heat the facility. Ernest’s team budgeted for
the propane and arranged for supervision of youth in exercise, weight lifting and sports
activities. As he says:

So what we want to do is we want to be the preventative force out there, you
know, and let you know that, hey, you’re responsible enough to know better and I
think, like I said, concentrate on your kids. You know, they’re the ones of our
future. What we need to do then is just to keep that preventive measure going for
future generations because again, like I said, these are going to be our future
leaders.
The recent cluster of youth suicides at Standing Rock is one of the most heartbreaking developments. Access to services for mental health problems and suicide attempts is 40 to 75 miles away in Bismarck. This is particularly vexing to Michael:

Personally, I think they need a youth facility here because they do send them to Bismarck. Parents don’t have no ride up there. If they could put it here, at least, you know, they could get a ride ... transport them that far or something so they could actually sit there and, you know, deal with their child. I mean, get the help for the child that the child needs and the parent could sit back and see what part she needs to ... you know ... fix so that this child, because there’s several that do it over and over ... I mean. You know, it’s not a, what do they call it, anger marks or whatever ... when they’re angry. Yeah, they need something like that and I’m sure we’ll be ... and if they get something like that, I’m sure we’ll be right there helping.

Follow up for psychiatric care in Bismarck often involves return appointments three times a week. A family member may have to take off work for three days in order for the patient to keep the appointments, which is unlikely.

Millions of dollars dedicated to health care for Standing Rock Tribal members is spent on services in Bismarck. Dialysis is provided to 28 patients at a cost of $52,000 or $1.5 million dollars a year. The priority for treatment with IHS dollars is “life and limb.” This includes the complicated emergency services for victims of car crashes. In contrast, a needed hip or knee replacement would have to wait up to a year before it is even considered, while scarce resources are expended on severe problems. CHRs feel guilty using their private health insurance for care, when the people they serve wait for treatment, because IHS dollars cannot be stretched any further than lifesaving interventions. Health care is often the only industry in rural communities. In mainstream communities more of the dollars turn around within the community instead of being dedicated to tertiary care.
The CHRs are focused on turning the scenario around so that more of the dollars, which go to tertiary care off the reservation, go to prevention on the reservation. Fran has become involved in the state sponsored Women’s Way breast and cervical cancer screening program. She feels good when she hears people say, “They found cancer in my body, but I don’t have to go through chemo or they took it out or, you know, that’s really an awesome thing to hear is that cancer didn’t beat me; I beat it.” Sherry would like to see a similar effort focused on men, “I think we had a Men’s Way in McLaughlin, and there was 30 of them screened, and they said 21 ... 21 of them or 20 of them came back diagnosed with cancer.”

Access to medical services is a barrier to improving the health of the population. “I think if I was to change anything, I would ask for more doctors.... Some of the doctors that come to stay that get houses there, and they are there for about a year, and then our politics get involved,” says Fran. The politics may involve complaints to the Tribal Council or, as is rumored, rocky doctor-nurse relationships.

It has been many years since the CHR job has been a 24-hour a day, seven day a week schedule. Tell them that. They continue to be called out at night. Their so-called personal time may be devoted to youth activities, cooking for a funeral, or any number of other services to the people. It would be wrong to characterize them as super-heroes. They do represent something positive in their very presence in their communities. It can be difficult to realize that presence itself is a service, let alone all of the other activities they carry out.
CHAPTER FIVE
DISCUSSION OF FINDINGS

Findings are discussed in relation to Leininger’s theory of Culture Care Diversity and Universality, and to the literature on empowerment and primary health care. Care constructs derived from findings are explicated to include potential action modes. Implications for future research and practice are delineated. Finally, reflection on strengths of the study and insights related to the ethnonursing and participatory action research methods are included.

Entry to Leininger’s Sunrise Enabler (Appendix A) was at the level of generic and professional care practices. Influences of worldview, religion, values, kinship, economic, educational, technological, and political factors on CHR practices were discovered in the context of ethnohistory and the environment.

Research Findings Related to Theory and Research

Theme One – Poverty, Kinship and Spirituality

Poverty, kinship issues and spiritual beliefs influence CHR practice. Theme One relates to the first research question regarding the influence of worldview, ethnohistory, and religious and philosophical factors on CHRs’ culture care practices. CHRs differ intra-culturally in worldview and religious beliefs. This finding is significant in that it obviates the stereotyping of American Indians in mass culture, often influenced by films, as representing one image or another of Indian beliefs and practices. Intra-cultural
variation echoes Garro’s (1996) findings among the Anishinaabe regarding causal explanations for diabetes based on worldview. Within the variation of beliefs, prayer is a constant as Struthers (2000) and Sanchez, Plawecki and Plawecki (1996) described. The use of ceremonies varies between Indian and Christian belief systems, but there also is remarkable similarity between Indian and Christian ceremonies. The use of prayer and ceremonies relates to the second research question regarding generic care practices of CHRs. The qualifications of a Native healer identified by Nora are consistent with Struthers’ (2000) findings of similar actions and beliefs among Ojibwa healers.

Ethnohistory revealed persistent attacks on Indian culture through the government policies of allotment and assimilation (Dixon, 2001; Jones, 2006; Shelton, 2001; Zechetmayr, 1997). Many adults were relocated to urban areas and children were sent to Indian schools. Major economic and social disruptions were the results of these policies. Generations which experienced relocation, whether as children or adults, lost cultural grounding. The persistence of poverty over the centuries since colonization is one causal factor in continuance of health disparities among American Indians, as described by Jones (2006). The impact of this poverty, including high rates of alcoholism, depression, suicide and domestic violence (Shelton, 2001), has precipitated severe disruption of family systems and a culture of entitlement among some.

Theme Two – Inner Strength

CHRs perform multifaceted jobs with inner strength and positive outlook, but at some cost to themselves. The values, which sustain CHRs, generosity, respect, attitude toward nature and courage, are consistent with the findings of Sanchez, Plawecki and
Plawecki (1996) in their study of Navajo and Sioux people. These values and others revealed by this study correspond to the fourth research question about impact of values and beliefs on generic and professional care practices, and the fifth research question related to empowerment.

The strength which CHRIs demonstrate in the face of overwhelming odds against improving health for their people demonstrates empowerment as Perkins and Zimmerman (1995) described it, based on “individual strengths and competencies, natural helping systems, and proactive behaviors.” Foster-Fishman, Salem, Chibnall, Legler, and Yapchai (1998) described different pathways to empowerment, many of which can be seen in the Standing Rock CHR program. The CHRIs are free to develop individual competencies and program foci, including first responder trainer, youth work and alternatives to nursing home placement. They have autonomy, creativity, increasing professional knowledge, trust and respect in the community, and experience fulfilling work.

The CHRIs have a strong motivation to help others. The importance of this is consistent with the findings in a study of empowerment of migrant farm worker Camp Health Aids (Booker, Robinson, Kay, Gutierrez, Najera, & Stewart, 1997). It may be that motivation to help their people fuels the empowerment of CHRIs. The CHRIs continue to live in the context of their ancestors’ decimation by disease, starvation and relocation to reservations (Decker, 1991). As Ellen described the population, “they have always risen to the occasion, when there was a threat against people.”

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CHRs’ identification with their program, bridges from personal empowerment to group empowerment, consistent with the findings of Saegert and Winkel (1996), that a sense of community and mutual participation promote empowerment. Likewise, the work of McMillan et al. (1995) demonstrated that organizational climate is highly empowering of members and subsequently the group. The CHRs’ shared values, beliefs and practices are consistent with Leininger’s (2001) definition of a culture, and as such the CHR Program itself can be characterized as a subculture within the Tribe.

Theme Three – Improve Access

CHRs improve access to health care using scientific knowledge and skills and by connecting scarce medical resources to a population in need. Theme Three corresponds to research question three regarding CHR professional care practices. Issues of access to medical care impede fundamental role expressions of CHR. Their role is to bridge the gap between Western medicine and indigenous people (Satterfield, Burd, Valdez, Hosey, & Eagle Shield, 2002). The severe shortage and temporariness of medical staff causes frustration among the CHRs. The people they serve lack continuity of care from medical providers. Burdened with the knowledge that access to care must change, the CHRs are unable to effect that change by recruiting more providers.

Other roles identified in the University of Arizona study (1998) are fulfilled by the CHRs including informal counseling and social support, provision of culturally relevant health education, advocacy for the individual and community, building of individual and community capacity to promote health, and provision of direct services. It
is more difficult to assure that people get the services they need for a variety of reasons, which include lack of funds and the distance to tertiary care.

The professionalism of CHRs at Standing Rock has developed markedly in the past ten years. They address problems such as chronic illness on a population level as is demonstrated in their community profiles. By minimizing transportation, they are freed to monitor physical changes in their elderly clients. While they have developed a good grasp of Wasichu medicine, they have not abandoned their Indian identity. They have become experts at translating sophisticated scientific information into the common parlance. Their methods of working with clients are consistent with the traditions of respect for the elderly and influencing behavior change through indirect communications.

Theme Four - Health Promotion in Remote Areas

CHRs promote health in proximity to remote populations and through collaboration with other services. Theme Four reveals data associated with research question three, related to professional care practices, and question five regarding empowerment as a principle of primary health care. Ken’s emphasis on training is similar to Hecker’s (1997) study of aboriginal health workers in Australia, in which a consistent and high standard of training was identified as a major need in increasing the efficacy of the outreach workers. As the Standing Rock CHRs advance in role performance as case managers and in academic credentials, they approach professional status. Just as important during this process, as the role of the CHR evolves, the CHRs do not sacrifice their identification with their tribe; they still belong among the other members of the tribe.
The principles of primary health care are demonstrated in Theme Four (WHO, 1978). While access to medical services is severely limited, the CHRs do extend care to the family and home. The empowerment of the CHRs demonstrates community involvement in health. The CHRs’ access to current technology has increased dramatically in the last ten years. They began by acquiring glucometers and have progressed to defibrillators and laptops. The CHRs focus on primary prevention in their work with youth and as health educators; they demonstrate secondary prevention as first responders; and they perform tertiary prevention with their caseloads of elderlies. Their connections to a wide variety of public and private organizations and services, locally and nationally, demonstrates a multi-sectoral approach to health care.

Modes of Action

Culture Care Preservation and Maintenance

It is necessary to recognize the strength of the American Indian’s traditional beliefs, in both Indian and Christian expression. While the research did not identify a secular expression of tradition, acknowledging that possibility, plus other interpretations of tradition, including so-called “new age” practice, would be important. Approaching American Indians as individuals and inquiring about their preferred mode of care in relation to their religious beliefs is an ethical imperative. The base of shared values is a major cultural strength, which should be reinforced. Support for the kinship system and respect for elders and elderlies should be given in any health intervention.
**Culture Care Accommodation or Negotiation**

The use of pharmaceuticals and herbal medicine together is a major area for negotiation between Native and Western medicine. Formularies of herbal medicine can be helpful in this endeavor; however, too little is known about the actual interaction of medicines from different traditions. A high level of patient trust in the provider is necessary in order to obtain disclosure of the use of Native treatment. Much has been accomplished in identifying needed accommodations during the practice of ceremonies such as the Sun Dance and the sweat lodge. This information can only be put into use with the knowledge that participation in the ceremony is planned, again requiring the patient’s trust in the provider to disclose the information. Building trust among patients requires an investment of time to listen to the patient’s explanatory model of their condition, describe therapies in an understandable way, and answer questions. Health care becomes truncated when communication is rushed.

**Culture Care Repatterning or Restructuring**

The hope is that a focus on the development of youth and a focus on prevention will result in the next generation of Indian people taking a more active role in their own health care. This would decrease the need for enabling by care providers, including CHRs and professionals. The delivery of health care needs major restructuring including resolving the constant turnover of providers, the loss of follow-up between tertiary care settings and the reservation, and the concentration of limited funds on tertiary care. Few resources are left to fund an active prevention program.
Recommendations for Practice

Nurses should partner with CHRs in the provision of health to Indian populations. This includes all levels of care from primary to tertiary. The CHRs recognize that there is a breakdown of communications between Wasichu providers and patients. Where rural residents lack direct access to medical care providers in an overly stressed system, CHRs can be effective in connecting with nurses in public health, ambulatory clinics, and hospitals. Indeed, that relationship between CHRs and nurses led to the partnership described in this study.

A number of prevention strategies are suggested by the research. Rekindling the tradition of respect for the plant or animal, which had to die in order to provide food is a cultural value, which can be applied to efforts to create behavior change. The CHRs’ own stories of their youth and upbringing can inspire others. The CHRs continue to be role models to other members of their tribes and can capitalize on their status. If IHS funding levels continue to remain flat or decline, alternative sources, such as private foundation funding, should be sought. The success of planning and building the gymnasium in one the districts with foundation funds is an example of a dramatic increase in resources for health, and should be emulated.

Recommendations for Research

Individual CHR narratives include stories waiting to be told. Literature based on the CHRs’ life experiences would be very informative to providers of Western medicine, other outreach workers among other ethnic groups, and translational researchers looking to bridge from bench to bedside. The CHRs have encountered enormous obstacles in
doing their work and raising their families. The oldest CHRs began working in 1968. Their life histories would include observations of major changes in reservation life. Oral histories of survivors of Indian schools and urban relocation would contribute to research on posttraumatic stress disorder and resilience.

Knowing the impact of current environments on health in reservation communities would inform planners what is needed when future planning models for schools, institutions and housing are being developed. Exercise is a major preventive health measure that improves outcomes for many chronic illnesses. Most buildings in reservation communities are temporary and prefabricated. Multi-purpose structures could contribute to opportunities for exercise.

The interaction of herbal and pharmaceutical company medications is largely unknown. There is clear efficacy in herbal medicine, indeed modern formularies are based on herbal origins. Scientific testing of the interaction of herbal and mainstream drugs is needed.

On the policy level, the impact of draining health care dollars from reservations to tertiary care facilities in Wasichu cities should be explored. Millions of dollars that Congress expects to improve Indian health is concentrated in tertiary care, which is provided, in a health care system, which not only offers minimal outreach to the reservation community, but excludes the realities of family life and poverty in discharge planning. The economic impact of this health care in jobs, goods and services accrues to the Wasichu city, not the reservation. An ecological model of retaining more of the treatment options at the reservation would contribute to jobs and improve outcomes of
care, by nesting it in proximity to family and community supports, particularly in the field of mental health. Such a model should be tested for impact on outcomes and the reservation economy.

**Strengths and Methodological Insights**

Participatory action research, which is focused on empowerment, requires a longer period of time than most research funding can provide. The strength of this endeavor was that it was undertaken without a research agenda, but as a service, and evolved consistent with the ethic of participatory action research. The focus of the research is important and there is a dearth of research on the subject of American Indian CHRs. Conceptualizing the effort as research was based on a nursing model of theory and research method, that of Madeleine Leininger. The value for the World Health Organization primary health care model was affirmed as appropriate for underserved populations in the United States.

A number of insights developed in the course of the research. First, while the author could envision the project as consistent with the participatory action theory model selected by the Aberdeen Area Tribal Chairmen, I was unprepared for the challenge of the request for “co-ownership” of the data. At the point that I acceded to that request, I was unsure of how that would be implemented in a manner consistent with Institutional Review Board requirements. “De-identification” of the data in the transcripts and the use of pseudonyms met the criteria for confidentiality, while clear notification of subjects of the return of the data to the tribe in the consents gave them the option to limit their
responses to interview questions, if necessary. I perceived no chilling effect among the subjects from the requirement to return data to the tribe.

Several CHRs began their interview with statements that their mind just went blank, or they didn't know what to say. I took these statements at face value and thought the data would be limited by shyness in response to being taped. In fact, when I had the transcripts completed, I discovered there was much more richness than I anticipated.

My use of the terminology, "Western medicine," had an unintended effect. In retrospect, I think the CHRs understood the appellation "Western" as Wasichu medicine. Our communications were less clear in relation to the term "medicine." I meant medicine as the discipline or field of medicine. Eventually I realized that the CHRs were hearing medicine as pharmaceuticals. My attempt to correct that impression by saying, "I mean the discipline of medicine," had no effect on clarifying my meaning. Those times when I referred to how "health care" is delivered, elicited more complete responses from the CHRs.

**Conclusion**

American Indians continue to demonstrate some of the greatest disparities in health status compared to the general population in the United States. Community health representatives can play a pivotal role when empowered to address this challenge. The primary health care model of the World Health Organization offers other avenues besides medical care for improving health status among disadvantaged populations. Nurses can influence role development among CHRs and should partner with them to enhance health care among the Indian populations of the United States.
APPENDIX A

SUNRISE MODEL ENABLER
Leininger's Sunrise Enabler to Discover Culture Care

Culture Care

Worldview

Cultural & Social Structure Dimensions

Kinship & Social Factors

Cultural Values, Beliefs & Lifeways

Political & Legal Factors

Environmental Context, Language & Ethnolinguistic

Influences

Care Expressions

Patterns & Practices

Religious & Philosophical Factors

Economic Factors

Technological Factors

Educational Factors

Holistic Health / Illness / Death

Focus: Individuals, Families, Groups, Communities or Institutions in Diverse Health Contexts of

Generic (Folk) Care

Nursing Care Practices

Professional Care-Cure Practices

Transcultural Care Decisions & Actions

Culture Care Preservation Maintenance

Culture Care Accommodation Negotiation

Culture Care Repatterning Restructuring

Culturally Congruent Care for Health, Well-being or Dying

APPENDIX B

POSSIBLE PROCESS STEPS WITH NATIVE PEOPLE
APPENDIX C

LETTER OF APPROVAL FROM INSTITUTIONAL REVIEW BOARD
Dear Ms. Tyree,

Thank you for submitting the research project entitled: Culture Care Values, Beliefs and Practices Observed in Empowerment of American Indian Community Health Representatives, for expedited review by the Institutional Review Board for the Protection of Human Subjects. After careful examination of the materials you submitted, we have approved this project as described for a period of one year. The IRB has approved the final version of the consent form and enclosed is an official stamped version of the form. Please make copies of this original form and use it for obtaining consent from participants.

Approximately eleven months from your initial review date, you will receive a renewal notice stating that approval of your project is about to expire. This notice will give you detailed instructions for submitting a renewal application. If you do not submit a renewal application prior to June 21, 2007, your approval will automatically lapse and your project will be suspended. When a project is suspended, no more research or writing regarding human subjects may be done until the project is reevaluated and re-approved. I recommend that you respond to these annual renewals in a complete and timely fashion.

This review procedure, administered by the IRB, in no way absolves you, the researcher, from the obligation to immediately inform the IRB in writing if you would like to change aspects of your approved project (please consult our website for specific instructions). You, the researcher, are respectfully reminded that the University's ability to support its researchers in litigation is dependent upon conformity with continuing approval for their work. Should you have questions regarding this letter or general procedures, please contact the Compliance Manager at [contact information]. Kindly quote File #73643, if this project is specifically involved.

With best wishes for the success of your work,

Dr. Raymond H. Dye Jr.
Chair, Institutional Review Board

cc: Gloria Jacobson, Ph.D., Nursing

July 13, 2006
APPENDIX D

COMMUNITY HEALTH REPRESENTATIVE RECRUITMENT LETTER
Dear Mr. ...

You have been identified from attendance records of the UND Nursing Center as a Community Health Representative who has received training in a Nursing Center sponsored workshop. I am writing at this time to invite you to participate in a research study entitled “Culture Care Values, Beliefs and Practices Observed in Empowerment of American Indian Community Health Representatives.” CHRs walk in two worlds, the American Indian and Western medical approaches to health care. The purpose of the study is to learn how strengths of traditional Indian and Western medicine can be used to improve people’s health. Many people change their health behaviors because of your influence. It is important to know how that happens, and why CHRs are essential health personnel. The attached flyer invites you to participate in a Talking Circle of about 2 hours about the CHR role. You will also be invited to participate in an individual interview of 1-1½ hours about being a CHR. A buffet lunch will be provided after the Talking Circle; and a $10. long distance calling card will be given after participation in the interview. You can choose not to participate in the study and still continue to receive services of the UND Nursing Center. There is no penalty for not participating. Please consider this study as an opportunity to highlight CHR work. Thank you for thinking about participating.

Sincerely,

Elizabeth A. Tyree, RN, MPH
Director, Nursing Center
APPENDIX E

TRAINER RECRUITMENT LETTER
Dear Mr. ...

You have been identified from records of the UND Nursing Center as a trainer who has presented in a Nursing Center sponsored workshop. I am writing at this time to invite you to participate in a research study entitled “Culture Care Values, Beliefs and Practices Observed in Empowerment of American Indian Community Health Representatives.”

CHRs walk in two worlds, the American Indian and Western medical approaches to health care. The purpose of the study is to learn how strengths of traditional Indian and Western medicine can be used to improve people’s health. Many CHRs change their health care practices because of your influence. It is important to know how that happens, and why CHRs are essential health personnel. You are invited to participate in an individual interview of 1-1½ hours about being a CHR trainer. You will be compensated with $10. for participating in the interview. You can choose not to participate in the study and still continue to provide services through the UND Nursing Center. There is no penalty for not participating.

Please consider this study as an opportunity to highlight CHR work. Thank you for thinking about participating. I will contact you in the near future regarding an interview.

Sincerely,

Elizabeth A. Tyree, RN, MPH
Director, Nursing Center
WHO: COMMUNITY HEALTH REPRESENTATIVES

WHAT: CHR TALKING CIRCLE

WHEN: 9/12/06

10:00 AM

WHERE: PRAIRIE KNIGHTS HOTEL

WHY: WHAT ARE CHR ROLES AND WORK?

HOW? LATER-BUFFET LUNCH
APPENDIX G

KEY PARTICIPANT INFORMED CONSENT
CONSENT TO PARTICIPATE IN RESEARCH

Project Title: Culture Care Values, Beliefs and Practices Observed in Empowerment of American Indian Community Health Representatives

Researcher: Elizabeth A. Tyree

Faculty Sponsor: Dr. Gloria Jacobson

Introduction:
You are being asked to take part in a research study being conducted by Elizabeth Tyree for a dissertation under the supervision of Dr. Gloria Jacobson of the School of Nursing at Loyola University of Chicago.
You are being asked to participate because you have received training as a Community Health Representative (CHR) from the University of North Dakota (UND) Nursing Center.
Approximately 12 to 15 current or former CHRs from the Standing Rock Reservation will be asked to participate in the study.
Please read this form carefully and ask any questions you may have before deciding whether to participate in the study.

Purpose:
The purpose of the study is to identify how the CHR role has developed as a bridge between the ways of Native and Western medicine.

Procedures:
If you agree to be in the study, you will be asked to:
- Have your words audio-taped.
- Participate in a Talking Circle about the CHR role for about 2 hours.
- Have an individual interview of about 1 ½ hours about: the CHR role; Native healing ways; Western medicine; what changes you think should happen in people's use of Native and/or Western medicine; how the CHR role has changed your ideas about health.

Risks/Benefits:
There are no known risks involved in being part of the research besides those you experience in everyday life.
You may benefit by improving the cultural sensitivity of Western medicine providers. CHRs and tribes in general may benefit from other people, particularly funding agencies, knowing what you do.

Compensation:
Buffet lunch will be provided for the Talking Circle. Participants in the individual interview will receive a $10. long distance calling card. Withdrawal from the study at a later date will not affect this compensation.
Confidentiality:
The Standing Rock Sioux Tribe and the researcher will have co-ownership of the data.

Tribal Ownership:
- The typed transcripts without identification of the people who spoke will be returned to
  the Tribe.
- The transcripts will be delivered to the Chairman of the Health Committee at the Health
  Committee office.

Researcher Ownership:
- When audiotapes are typed, names will be changed on the transcripts.
- Besides the researcher, her teachers may view the transcripts and notes as they help her
  learn the research process. Institutional Review Board auditors may also have access to
  the data.
- Requirements for mandatory reporting of child abuse will be followed.
- The tapes and transcripts will be stored in a locked cabinet at the UND College of
  Nursing, available only to the researcher. Consent forms will be stored separately from
  transcripts. Audiotapes and consent forms will be shredded after 3 years.

Voluntary Participation:
Participation in this study is voluntary. If you do not want to be in this study, you do not have to
participate. Even if you decide to participate, you are free not to answer any question or to
withdraw from participation at any time without penalty. The decision to not participate will not
affect your current relationship with the UND Nursing Center or any services which the Nursing
Center might provide in the future.

Contacts and Questions:
If you have any questions about this study, please feel free to contact the researcher, Elizabeth
Tyree, at [email protected] and/or the faculty sponsor, Dr. Gloria Jacobson at [email protected].

If you have questions about your rights as a research participant, you may contact the Compliance
Manager in Loyola’s Office of Research Services at [email protected]; and the University of North
Dakota Office of Research Development and Compliance at [email protected].

Statement of Consent:
Your signature below indicates that you have read and understood the information above, have
had an opportunity to ask questions, and agree to participate in this research study. You will be
given a copy of this form to keep for your records.

Participant’s Signature

Researcher’s Signature

Witness

Date

Date

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CONSENT TO PARTICIPATE IN RESEARCH

Project Title:  Culture Care Values, Beliefs and Practices Observed in Empowerment of American Indian Community Health Representatives

Researcher:  Elizabeth A. Tyree

Faculty Sponsor:  Dr. Gloria Jacobson

Introduction:
You are being asked to take part in a research study being conducted by Elizabeth Tyree for a dissertation under the supervision of Dr. Gloria Jacobson of the School of Nursing at Loyola University of Chicago.
You are being asked to participate as a general informant because you are an elder in the community who has had contact with Community Health Representatives.
Approximately 3 to 4 elders will be asked to participate in the study.
Please read this form carefully and ask any questions you may have before deciding whether to participate in the study.

Purpose:
The purpose of the study is to identify how the CHR role has developed as a bridge between the ways of Native and Western medicine.

Procedures:
If you agree to be in the study, you will be asked to:
- Have your words audio-taped.
- Participate in a Talking Circle about the CHR role for about 2 hours.

Risks/Benefits:
There are no known risks involved in being part of the research besides those you experience in everyday life.
You may benefit by improving the cultural responsiveness of Western medicine providers. CHRs and tribes in general may benefit from other people, particularly funding agencies, knowing what CHRs do.

Compensation:
Buffet lunch will be provided for the Talking Circle. Withdrawal from the study at a later date will not affect this payment.

Confidentiality:
The Standing Rock Sioux Tribe and the researcher will have co-ownership of the data.
Tribal Ownership:
• The typed transcript without identification of the people who spoke will be returned to the Tribe.
• The transcripts will be delivered to the Chairman of the Health Committee at the Health Committee office.

Researcher Ownership:
• When audiotapes are typed, names will be changed on the transcripts.
• Besides the researcher, her teachers may view the transcripts and notes as they help her learn the research process. Institutional Review Board auditors may also have access to the data.
• Requirements for mandatory reporting of child abuse will be followed.
• The tapes and transcripts will be stored in a locked cabinet at the UND College of Nursing, available only to the researcher. Consent forms will be stored separately from transcripts. Audiotapes and consent forms will be shredded after 3 years.

Voluntary Participation:
Participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free not to answer any question or to withdraw from participation at any time without penalty. The decision to not participate will not affect your current relationship with the UND Nursing Center or any services, which the Nursing Center might provide in the future.

Contacts and Questions:
If you have any questions about this study, please feel free to contact the researcher, Elizabeth Tyree, at [contact information], and/or the faculty sponsor, Dr. Gloria Jacobson at [contact information].
If you have questions about your rights as a research participant, you may contact the Compliance Manager in Loyola’s Office of Research Services at [contact information]; and the University of North Dakota Office of Research Development and Compliance at [contact information].

Statement of Consent:
Your signature below indicates that you have read and understood the information above, have had an opportunity to ask questions, and agree to participate in this research study. You will be given a copy of this form to keep for your records.

Participant’s Signature ___________________________ Researcher’s Signature - Witness ___________________________

Date _________ Date _________
APPENDIX I

TRAINER INFORMED CONSENT
CONSENT TO PARTICIPATE IN RESEARCH

Project Title: Culture Care Values, Beliefs and Practices Observed in Empowerment of American Indian Community Health Representatives

Researcher: Elizabeth A. Tyree

Faculty Sponsor: Dr. Gloria Jacobson

Introduction:
You are being asked to take part in a research study being conducted by Elizabeth Tyree for a dissertation under the supervision of Dr. Gloria Jacobson of the School of Nursing at Loyola University of Chicago. You are being asked to participate as a general informant because you have provided or consulted about training for Community Health Representatives (CHRs), which was conducted by the University of North Dakota (UND) Nursing Center. Approximately 8 to 10 general informants will be asked to participate in the study. Please read this form carefully and ask any questions you may have before deciding whether to participate in the study.

Purpose:
The purpose of the study is to identify how the CHR role has developed as a bridge between the ways of Native and Western medicine.

Procedures:
If you agree to be in the study, you will be asked to:
- Have your words audio-taped.
- Have an individual interview about: the CHR role; Native healing ways; Western medicine; what changes you think should happen in people’s use of Native and/or Western medicine; how the CHR role has changed your ideas about health.

Risks/Benefits:
There are no known risks involved in being part of the research besides those you experience in everyday life. You may benefit by improving the cultural responsiveness of Western medicine providers. CHRs and tribes in general may benefit from other people, particularly funding agencies, knowing what CHRs do.

Compensation:
General informants will be paid $10. cash for participation in the interview. Withdrawal from the study at a later date will not affect this payment.

Confidentiality:
The Standing Rock Sioux Tribe and the researcher will have co-ownership of the data.

Tribal Ownership:
• The typed transcript without identification of the people who spoke will be returned to the Tribe.
• The transcripts will be delivered to the Chairman of the Health Committee at the Health Committee office.

Researcher Ownership:
• When audiotapes are typed, names will be changed on the transcripts.
• Besides the researcher, her teachers may view the transcripts and notes as they help her learn the research process. Institutional Review Board auditors may also have access to the data.
• Requirements for mandatory reporting of child abuse will be followed.
• The tapes and transcripts will be stored in a locked cabinet at the UND College of Nursing, available only to the researcher. Consent forms will be stored separately from transcripts. Audiotapes and consent forms will be shredded after 3 years.

Voluntary Participation:
Participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free not to answer any question or to withdraw from participation at any time without penalty. The decision to not participate will not affect your current relationship with the UND Nursing Center or any services, which the Nursing Center might provide in the future.

Contacts and Questions:
If you have any questions about this study, please feel free to contact the researcher, Elizabeth Tyree, at [contact information], and/or the faculty sponsor, Dr. Gloria Jacobson at [contact information]. If you have questions about your rights as a research participant, you may contact the Compliance Manager in Loyola’s Office of Research Services at [contact information] and the University of North Dakota Office of Research Development and Compliance at [contact information].

Statement of Consent:
Your signature below indicates that you have read and understood the information above, have had an opportunity to ask questions, and agree to participate in this research study. You will be given a copy of this form to keep for your records.

Participant’s Signature

Researcher’s Signature

Witness

Date

Date
APPENDIX J

TRIBAL COUNCIL RESOLUTION
May 15, 2006

The Chair, IRB, c/o Research Services
Loyola University of Chicago
620 N. Sheridan Rd
Chicago, Illinois 60626

Dear Professor and Chairperson:

This is to verify that Elizabeth Tyree may approach Community Health Representatives in the conduct of her dissertation. "Culture Care Values, Beliefs, and Practices Observed in Empowerment of American Indian Community Health Representatives." Her research follows nine years of Community Health Representative collaboration with the University of North Dakota Nursing Center which she directs. Nursing Center activity with CHRs has always been at the direct request of the CHRs and planned in collaboration with CHRs. I understand that Ms. Tyree's research will explore how the CHR role has developed as a bridge between Native ways of healing and Western medicine. She will tape record a Talking Circle discussion with CHRs and elders, individual interviews with CHRs who received training from the UND Nursing Center, and individuals who provided training for CHRs through the Nursing Center. I have reviewed the research protocol for this study and believe it respects the rights of individuals to participate as long as they are comfortable with the research process.

I support Ms. Tyree's plan for her dissertation and will work with her to ensure that the research is carried out in a respectful way.

Sincerely,

Ron His Horse is Thunder, Chairman
Standing Rock Sioux Tribe

CC: Jesse Taken Alive, Chairman
    HEW Committee
APPENDIX K

COPYRIGHT PERMISSION FOR SUNRISE ENabler
I apologize if I have not responded to this prior to today.

You are welcome to use the diagram as long as it is for educational purposes.

Best regards,

John Vanderlaan

From: Liz Tyree
Sent: Tuesday, February 06, 2007 11:12 AM
To: [removed]
Subject: Sunrise Model

This is to request permission to print the Sunrise Enabler in my dissertation entitled Culture Care Values, Beliefs and Practices Observed in Empowerment of American Indian Community Health Representatives which is being completed at Loyola University Chicago.

Thank you for your attention to this request.

Elizabeth A. Tyree, PhD(c), MPH, RN
Clinical Associate Professor and Chair, Family and Community Nursing
University of North Dakota
College of Nursing
[removed]
APPENDIX L

COPYRIGHT PERMISSION FOR POSSIBLE PROCESS

STEPS WITH NATIVE PEOPLE
Liz Tyree - RE: Figure

From: Liz Tyree
To: William L. Freeman, MD, MPH, CIP
Subject: RE: Figure


Liz,

I consider my presentation and PowerPoint to be "public domain." So, yes, go ahead. (& thanks for asking!)

Bill

> -----Original Message-----
> From: Liz Tyree [m
> Sent: Monday, June 27, 2005 11:37 AM
> To: [m
> Subject: Figure
> 
> This is to request permission to copy the figure "Possible process steps with Native people" on page six of the PowerPoint handout which accompanied your presentation at the "How to Conduct research in AI/AN Communities" conference, June 16-17, 2005.
> 
> I am preparing the first draft of the dissertation proposal which must be approved before seeking IRB approval.
> 
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REFERENCES


VITA

Elizabeth Maly Tyree was born and raised in Milwaukee, Wisconsin. She obtained her bachelor’s degree at Marquette University and Master of Public Health at the University of Michigan. She was prepared as a Pediatric Nurse Practitioner at the University of Colorado in 1970. Ms. Tyree was inducted into Sigma Theta Tau International Honor Society for Nursing in 1991, and in Alpha Sigma Nu National Jesuit Honor Society in 2003. She completed her Doctor of Philosophy degree in the Marcella Niehoff School of Nursing at Loyola Chicago in 2007.

Ms. Tyree’s professional career has focused on maternal and child health, public health and community based care of children’s health. She was a leader in the development and implementation of the nurse practitioner role in the states of Colorado, Michigan, Wisconsin and North Dakota. She has been honored several times for her professional work. For example, she has received the Sigma Theta Tau Region 2 “Mentor Award” and the Eta Upsilon Chapter “Caring Award.” She is serving a four year term on the National Advisory Council on Nursing Education and Practice.

Prior to beginning her doctoral work, Ms. Tyree moved to Grand Forks, North Dakota. She is currently a faculty member and department chair at the University of North Dakota College of Nursing where she also directs the Family Nurse Practitioner Program and Nursing Center.
The dissertation submitted by Elizabeth Maly Tyree has been read and approved by the following committee:

Dr. Gloria Jacobson, Director
Associate Professor of Nursing
Loyola University Chicago

Dr. Judith Jennrich
Associate Professor of Nursing
Loyola University Chicago

Dr. Karen Egenes
Associate Professor of Nursing
Loyola University Chicago

Dr. Nancy White
Professor of Nursing
University of Northern Colorado

The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.