PARTICIPATORY ACTION RESEARCH AND HEALTH PROMOTION:

THE GRANDMOTHERS' STORY

A Thesis Submitted to the College of

Graduate Studies and Research

in Partial Fulfillment of the Requirements

for the Degree of Doctor of Philosophy in the

Department of Community Health and Epidemiology

College of Medicine

University of Saskatchewan

Saskatoon

By

Geraldine Dickson

Spring 1997

Canada

UNIVERSITY OF SASKATCHEWAN

College of Graduate Studies and Research

SUMMARY OF DISSERTATION

Submitted in partial fulfillment
of the requirements for the

DEGREE OF DOCTOR OF PHILOSOPHY

b y

GERALDINE DICKSON

Department of Community Health and Epidemiology
College of Medicine
University of Saskatchewan

Spring 1997

Examining Committee:

Dr. A. Ryan	Dean/Associate x Dean/Dean's Designate, Chair College of Graduate Studies and Research
Dr. B. Habbick	Chair of Advisory Committee Department of Community Health and Epidemiology
Dr. K. Green	Advisor, Department of Community Health and Epidemiology
Ms. J. Feather	Department of Community Health and Epidemiology
Dr. N. Gerrard	College of Medicine
Professor V. St. Denis	College of Education

External Examiner:

Dr. Mary O'Connor
McMaster Research Centre for the Promotion of Women's Health
McMaster University
Hamilton, Ontario L8S 4M4

PARTICIPATORY ACTION RESEARCH AND HEALTH PROMOTION: THE GRANDMOTHERS' STORY

This inquiry is a case study of the utility and appropriateness of participatory action research both as a research methodology and as an intervention for health promotion. In the study, I examined the effects of participating in a health promotion project, one aspect of which was a participatory health assessment. I also described in detail the experience of using participatory action research to conduct the health assessment. The study was carried out over 2.5 years in a health promotion project for older, urban, Aboriginal women (hereafter known as the grandmothers) sponsored by the local community clinic. The overall purpose of that project was to examine the health needs of those women and respond through health promoting programming.

The grandmothers were the central participants in the study. Participation in the project and health assessment contributed to a number of changes in them which I have categorized as: personal cleansing and healing; connecting with self; acquiring knowledge and skills; connecting within the group; and external exposure and engagement. "Participation" was identified as the central influence on the outcomes, "action" as a theme interwoven throughout, and "opportunity", "encouragement", and "mediation" as key characteristics of the project and research environment. This experience of using participatory action research demonstrated its success as an approach to conducting a health assessment which was acceptable to this group of people and congruent with the health promotion project in which it was embedded. The analysis of the experience highlights both tensions and accomplishments. The findings of the health assessment are published in a separate document.

PERMISSION TO USE

In presenting this thesis in partial fulfillment of the requirements for a postgraduate degree from the University of Saskatchewan, I agree that the libraries of this university may make it freely available for inspection. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work or, in their absence, by the head of the department or the dean of the college in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis.

Requests for permission to copy or to make other use of material in this thesis in whole or part should be addressed to:

Head of the Department of Community Health and Epidemiology
University of Saskatchewan
Saskatoon, Saskatchewan   S7N 5E5

Abstract

This inquiry is a case study of the utility and appropriateness of participatory action research both as a research methodology and as an intervention for health promotion. In the study, I examined the effects of participating in a health promotion project, one aspect of which was a participatory health assessment. I also described in detail the experience of using participatory action research to conduct the health assessment. The study was carried out over 2.5 years in a health promotion project for older, urban, Aboriginal women (hereafter known as the grandmothers) sponsored by the local community clinic. The overall purpose of that project was to examine the health needs of those women and respond through health promoting programming.

The grandmothers were the central participants in the study. Participation in the project and health assessment contributed to a number of changes in them which I have categorized as: personal cleansing and healing; connecting with self; acquiring knowledge and skills; connecting within the group; and external exposure and engagement. "Participation" was identified as the central influence on the outcomes, "action" as a theme interwoven throughout, and "opportunity", "encouragement", and "mediation" as key characteristics of the project and research environment. This experience of using participatory action research demonstrated its success as an approach to conducting a health assessment which was acceptable to this group of people and congruent with the health promotion project in which it was embedded. The analysis of the experience highlights both tensions and accomplishments. The findings of the health assessment are published in a separate document.

ACKNOWLEDGEMENTS

DEDICATION

This work is dedicated to the grandmothers who became my friends and were the source of my inspiration; my mother, Grace Pine; the memory of my father, Al Pine; my husband, Murray Dickson; and my sons, Brennan and Michael, all of whom I love.

TABLE OF CONTENTS

5.   SUMMARY, IMPLICATIONS, RESEARCH QUESTIONS

Appendices

List of Tables

List of Figures

Abbreviations

ER	External Researcher
HP	Health Promotion
PAR	Participatory Action Research
WHO	World Health Organization

1. Introduction

Despite advancing knowledge and technology, the basic problems of poverty, powerlessness, and ill health around the world remain unresolved. Absent is the political will to fundamentally restructure society for greater social justice and benefit. A majority of the earth's population continues to lie outside the world of privilege, prosperity, and health, yet it is the world inside which makes decisions that determine the lives of those marginalized. In principle, the health sector recognizes that social participation, self-determination, self-reliance, and empowerment enhance health and well-being, and these phenomena are cornerstones of primary health care, community development, and health promotion. In practice, more rhetoric is heard than reform or transformation is seen. People's participation in health is too often interpreted as compliance with programs rather than as a strategy for increasing relevancy and reducing inequities.

In the sphere of health research, there is an assumed, indirect, long-term benefit from research for the subjects of study, but typically researchers are not also practitioners, subjects do not participate in research other than as sources of data, and it falls to health practitioners to liaise between research and subjects/clients which they do to varying degrees. In most health research in this country, a participatory trend was not even considered until recently--well into the period of this inquiry. My study was motivated by the wish to learn more about the value and role of transformatory research, specifically participatory action research (PAR), for health promotion.

On paper, PAR has features complementary to the intent of health promotion.[1] PAR emphasizes empowerment of research participants through a) their participation in the research process; b) focusing on power relations within problems; and c) educating participants regarding the problems studied. Furthermore, PAR stresses a socio-political analysis to

1

problems, shifting the interpretation of problems from an individual to a societal context and an ecological relationship.

"Participatory action research" is the term used by Fals-Borda[2] to emphasize both the participative and action elements of research which is "openly ideological",[3] and thereby aims to transform socio-political inequities. This approach to social research integrates scientific investigation with education and political action.[4] It is an "interdisciplinary methodology enabling people to take control of their lives by combining formal and informal knowledge, and using that new knowledge to change their realities."[5] The literature also suggests that PAR produces knowledge which is valid and relevant because of its inclusion of popular knowledge and science and the participation of the people experiencing the problems studied.[6][7]

For the purposes of this study, PAR is defined as inquiry by ordinary people acting as researchers to explore questions in their daily lives, to recognize their own resources, and to produce knowledge and take action to overcome inequities, often in solidarity with external supporters.

Health promotion also emphasizes empowerment. The World Health Organization defines health promotion as "the process of enabling individuals and communities to increase control over the determinants of health and thereby improve their health."[8] This increased control is synonymous with empowerment. Health promotion attempts to expand and emphasize health maintenance and potential rather than focussing on disease and treatment. It recognizes the ecological aspects of well-being and challenges the health sector to look at the social determinants of health and tackle the multiple root causes of disease.

Most health promotion research employs conventional approaches in which the subjects of research function principally as sources of data. This role neither contributes directly to the subjects' empowerment nor encourages action by those experiencing the problems studied. Some writers have claimed that PAR is potentially a more appropriate and useful methodology

2

for health promotion research.[9] Little study has been done, however, on PAR's effects in promoting health in the research subjects.

This inquiry is a case study of the utility and appropriateness of PAR both as a research methodology and as an intervention for health promotion. It is a study of PAR within a particular population--urban, older, Aboriginal women (hereafter referred to as "grandmothers"*)--and focused on a particular issue--their health. By conducting a participatory health assessment of and with the grandmothers, I was able to describe and analyze the experience of PAR in practice, examine the impact on the grandmothers of participating in a health promotion (HP) and PAR project, and reflect on the implications of the further use of PAR for health promotion.

In my research proposal and throughout the first 1.5 years of the inquiry, the intended objective was to study the effects on participants of their participation in PAR. The original thinking in planning the study was to pursue my interest in PAR as a way of doing research consistent both with health promotion principles and yet health-promoting in its own right. Examples of PAR in the literature described discrete research initiatives. Yet when I set out to use PAR, it took on a slightly different look--it became one of the programming threads of the health promotion project. When the time came to interview the grandmothers regarding their participation, it was clear that they would not be able to separate out the impact of PAR (the participatory health assessment) from the rest of the project. Thus, the focus of the research question expanded to encompass the effects on the grandmothers of their participation in the project as a whole, including but not exclusive to the health assessment.

This thesis is laid out in five main chapters: introduction, literature review, methodology, findings and discussion, and summary and implications; each of which is further divided into subchapters and sections. Explanatory notes, denoted by symbols in the text, are at the end of each chapter. References cited in the text and appendices mentioned are found at the back of the document. The findings of the participatory health assessment are published under separate cover (see Appendix A).

3

1.1   Importance of the Study

Since PAR as it applies to health promotion is a recent development, research in this area is only beginning. The findings from this study may contribute to an understanding of PAR in health promotion research and programming. The experience from this inquiry may be useful in other related initiatives and fields. Applying PAR to a health setting may contribute to articulation of theory on the relationship between health and empowerment. Also, the results of this research experience will be communicated to others and may further the examination of various methodologies in health promotion research.

The present inquiry is exploring a model in which the roles of the researcher and subjects[†] are changed. Rather than have the researcher determine topics, questions, and methods, he/she creates an opportunity for the subjects and other participants to determine the substance, focus, and approach of the research. Depending on the utility of this methodology, the model may be applicable to fields other than health, such as counselling and education.

Because of my own interests, as described next in sections 1.2 and 1.3, and the intent of PAR, the project chosen for the application of PAR was a cross-cultural one involving a less empowered population. The study situation is complicated by these characteristics, but could pave the way for use of PAR in other challenging situations. As well, a project such as this may not be amenable to more conventional research approaches and so the trial of an alternative model was warranted.

Most of the literature on PAR deals with epistemological and political issues regarding its use, and pays less attention to the details of its design and implementation. From this inquiry, I attempted to document and describe these aspects more clearly. Since this study demonstrated the usefulness of PAR, this thesis and future publications may enhance the status of the methodology in academic and research circles. Moreover, since the research process was found to be useful to participants, they may be inspired to

4

conduct research in other areas, thereby contributing further to their empowerment.

1.2   External   Researcher

An external researcher (ER) in PAR is an active participant, bringing his/her own philosophy, experience, and understanding to the research.   As an ER, there are questions to ask oneself, explore, and make explicit, including: What leads me to be interested in this topic? How does my background contribute to or inform this research?[10]   Research is not neutral, and researchers influence their inquiries by their own ideology and biases,[11] the topics chosen, informed consent decisions made, kinds of questions posed, methods used, interpretations given, and ways in which findings are reported and disseminated.   This research is intended to be instructive for those interested in empowerment and socio-political change. My intentions, beliefs, and assumptions are included here so that not only is there "transparency of method"[12] in this study but also transparency of external researcher, allowing the reader to take my influence into account.

My interest in PAR comes from my personal value system, international health experiences spanning the years 1973 to the present, and from more recent involvement with Aboriginal people and health issues in Canada from 1985 to the present.   In the earlier years in developing countries and to a certain extent in Aboriginal health, the phenomena of primary health care, community development, and popular education were conceptualized and practised before they were discussed or used commonly in the non-Aboriginal Western world.   For me, it was a natural progression to view research through these conceptual frameworks and with the same set of principles and values which give priority to grassroots activity, popular knowledge, equity, and justice.   With this background, and with not having been imbued with the traditional research paradigm in my formal schooling, I have moved naturally into a research approach which has social change and justice as an explicit end, and is congruent with my experiences and values.

5

In Canada, I gravitated to working with Aboriginal people, initially as a community health nurse on a reserve, followed by a dual assignment at the university where, from my faculty position, I was seconded to coordinate a national project to attract and orient Aboriginal people into undergraduate nursing programs. Those involvements built on my personal situation of being a mother to my two Aboriginal sons and on my years working in developing countries where most people are underserved.

Despite my interest and background, there are limitations to my role in PAR. As a researcher who is external to the study community,[**] I must acknowledge to myself and to the other research participants the inherent contradiction between my role and presence in the research and the aim of PAR to reduce power inequities. I implicitly represent many aspects of contemporary and historical social, economic, and cultural dominance; I am White, middle-class, university educated, privileged, and from a patriarchal society and sector. This reality of who I am is a paradox: it is an advantage in that it gives me the opportunity both to learn about PAR and to become involved in a project in which its use may be appropriate and functional; yet it is a disadvantage because I am, inherently, an agent of racism and classism working with a group of less empowered participants who are the victims of these forms of oppression.

Gerrard[13] and Haig-Brown[14] have both considered, with perception and sensitivity, the position of the external researcher in the "border world," the area between "warring nations."[15] Haig-Brown justifies her work with Aboriginal people in that her efforts are on the side of the oppressed to combat racism, although she concedes her role is transitory and dependent on others' acceptance. Gerrard conducted research with women of colour in relation to their experiences in the mental health system. During her search for subjects, she was welcomed by a few ("I want you to do it . . . I think you should say it"),[16] insulted by some, and rejected by many. Out of the resulting mix of her anger, pain, and insight, Gerrard learned about her own racism and that of the women of colour with whom she talked. Both authors, in their respective articles, further illuminate various aspects of their roles as the external researcher.

6

Even though my own formal doctoral study program began in 1991, I had been grooming a research site for a number of years prior to that, in a project I helped create on spousal abuse. In fact, my perception of the obvious need to do research in this project with Aboriginal women on abuse had been a principal motivating factor for my return to graduate studies. A doctoral program would provide me with an opportunity to learn more about PAR, which seemed to be an appropriate methodology to use for this kind of study. A year-and-a-half into that initiative, the collaborative relationship for the research between an Aboriginal women's political association and myself ended and I, like Gerrard, felt confused and hurt. Gerrard's analysis of the dynamics of racism helped me understand, however, that despite my personal friendliness with the women in the association, there was a large chasm between us. In this one incident of thwarted collaboration, I felt the powerlessness that I think Aboriginal women must often feel. I felt dismissed not for who I am but because of racism. Gerrard advises honoring this resistance (of Aboriginal women in this case) as it is an achievement in gaining control by less empowered individuals. As well, she advises accommodating one's own feelings by seeing this resistance in the context of their reaction to racism in our society.

This thwarted first experience of trying to establish a participatory research relationship was a learning experience for me regarding the impact of my presence on a community with whom I was working. As I ventured into a second research opportunity, the one on which this thesis is based, I was aware that I would be seen again as part of the dominant oppressors, despite my well-meaning intentions and motives. Recognizing this reality of "researcher intrusion," I continually struggled to guide and conduct the research so that it represented and reflected the participants' styles, interests, and interpretations more than my own. This is not to imply that I could or would try to assume the persona of an Aboriginal person. I remained one who "respects the enormous differences between growing up as a member of a culture, and being part of the culture through participating in its day-to-day activities and through moments of vulnerability."[17] Since I may not have experienced some or many of the same concerns as the research participants, it was important for me to enter that world as well, that "culture." By "being inside the other culture, exposed

7

to its risks, touched by its joys,"[18] I am able to contribute to telling "a richer and more accurate story because it is a story from within the culture as well as from without."[19] Yet through my family life of raising my two Aboriginal sons, I had more in common with the women in the study than would be obvious, and this contributed to a bond between us.

1.3 Assumptions

Assumptions are what we take for granted, or suppose to be true, based on our ideology, values, and experiences. Playing vital although often invisible roles, underlying assumptions influence our communication and behaviour.[20] Prior to starting this inquiry, I identified a number of assumptions I held about PAR, adapting some from those proposed by Maguire:[21]

> some people are oppressed and disempowered; conversely, people need empowerment;

> the ability to shape both common and scientific knowledge is a source of power for dominant social groups;

> both researcher and subject come to the PAR process with knowledge and experience to contribute;

> power and control over decision-making and decision-taking in the research process can be shifted increasingly from the researcher to the subjects;

> ordinary people have an innate knowledge and, when provided with tools and opportunities, are capable of critical reflection and analysis, knowledge creation, and mobilizing human resources to solve socio-health problems.

Further assumptions which guided the research in this particular health setting with the grandmothers included:

8

Aboriginal control in any field is inextricably bound to redressing inequitable power relations with the dominant system;

Aboriginal people have the right to control their own health care system which emphasizes a holistic approach to health;

women retain the fundamental role of bearing and nurturing children, and maintaining family and community connections; these roles contribute to their function as natural leaders;

an external researcher representing the dominant culture does disturb and distort the study context, yet even so may be able to facilitate a reflective inquiry process.

1.4   Research   Objectives

Rather than set forth hypotheses to test, this inquiry was guided by two main objectives.

Primary objective: To examine the effects on the grandmothers of their participation in a health promotion project, one aspect of which was a participatory health assessment.

Secondary objective: To describe and critically reflect upon the experience of using PAR within a health promotion context.

As part of the health promotion project, our research team conducted a participatory health assessment of and with the grandmothers.   From that initiative, these two objectives could be addressed.

Endnotes:

*   "Grandmother" and "grandfather" are terms commonly used by Aboriginal people in our area to address older people in a respectful manner, and are not confined to use with blood relations, but are general designations.   Although the project had a more formal name, early on it became known as "the grandmothers' project" because the participants were thought of as "grandmothers."

9

†   Freire[22] makes an important distinction between viewing people as "objects" or as "subjects." Despite being labelled "subjects," people in much dominant paradigm research are viewed and treated as "objects"--to be studied, known, and acted upon ostensibly for their own ultimate good, but for the benefit of others. In PAR, people are full "subjects," active in decision-making, inquiring, knowing, taking action, and owning the knowledge, consequences, and other outcomes of the research.[23] Because of the confusion in the use of this term, in this study I generally use the term "participants" when describing experiences in the participatory health assessment, and "subjects" for the study of the effects of participation on the grandmothers because that research was consultative but was not PAR.

**   A community is defined as "a group of people who are socially interdependent, who participate together in discussion and decision making, and who share certain practices . . . that both define the community and are nurtured by it." [24]

2 Literature Review

This section reviews the literature on selected topics which relate to this inquiry, thereby supporting the rationale for the study. First, in order to situate PAR within this broader framework, I describe current research paradigms. Next, I discuss PAR in some detail, under a number of subtopics. The final section deals with health promotion, focussing on the elements of control and empowerment which link this field with PAR.

2.1 Research Paradigms

Researchers seeking to understand human behaviour have not only an array of research methods from which to choose, but more fundamentally, a choice of paradigms. Paradigms are mental windows or lenses through which we view the world. They are composed of certain belief categories, principally our understanding of the nature of reality (ontology), the nature of knowledge (epistemology), and the philosophy of the research process (methodology) which includes the assumptions and values that serve as a rationale for research.[25] [26]

Logically, a researcher would adopt a research paradigm according to his/her orientations on the nature of reality, knowing, and learning. Next, he/she would choose the research methodology with the right "fit" for the question, and finally choose the methods most appropriate to the particular purpose and population. In many cases, researchers are not aware of alternative paradigms and therefore continue to operate within the one paradigm with which they are familiar. Researchers interested in doing PAR, which arises from a more recent research paradigm, must often face criticism from others who are unfamiliar or disagree with this paradigm. The following section describes the differences between current research paradigms in order to situate PAR in relation to other research approaches.

Various research paradigm or methodology categorizations exist in the literature, including positivist/post-positivist,[27] [28] positivist/interpretive,[29] dominant/new paradigm,[30] quantitative/qualitative,[31] and conventional/constructivist.[32] From the options, I use a "positivist - post-positivist - transformative" categorization. Various authors[33] [34] [35] [36] [37] [38] [39] [40] [41] [42] [43] have compared and contrasted research paradigms. A summary of the categorization being used here is presented in table 1, adapted from Smith,[44] and from Guba[45] and Labonte and Robertson.[46]

The positivist paradigm, also called dominant, empirical-analytical, quantitative, and conventional, advocates using a natural, physical sciences approach to study the social and human world.[47] It is characterized by the following assumptions:

- objectivism: there is an objective universe, independent of observers, that can be explored by external inquiry and approximated by models;
- positivism: only data which is physically observable is the basis for what is scientifically "real;" and
- reductionism: scientific explanation requires breaking complex phenomena down to more basic elements.[48]

In the late nineteenth century, social scientists debated adopting this physical sciences approach. Those supporting the adoption, known as positivists, espoused a quantitative approach to social research, and focused on "instrument construction and rigour defined by statistical precision and replicability."[49] From the positivist perspective, the goal of social science is a search for overarching causal laws which would allow not only for the explanation of social phenomena but also for the ability to discover causes and to make predictions. Such laws would serve as a basis for any active intervention or social engineering to improve society.[50]

The post-positivist paradigm is the countermovement which developed in opposition to positivism, refuting its separation of facts and values, and

espousing interpretive understanding of concepts and questions as the goal of research. The emphasis of study is on searching for clarity and meaning of the whole life experience.

Whereas results of positivist research may seem shallow and abstract, those of post-positivism may beg questions about objectivity and representativeness. While the ability to predict outcomes is the goal and standard of positivism, the quality of post-positivism is judged by its ability to discover something about ourselves and our humanity--by a refinement in the debate.[51] Unlike positivism, power and control can be shared between the researcher and subjects in post-positivism. Yet in both these paradigms, some research may be of the type that Gerrard [52] has called "research abuse" and Reinharz [53] has critically labelled the "rape model of research" in which the purpose is the career advancement of the researcher, the inquiry methods are alienating to the subjects, and the findings are of little or no direct benefit to those researched.

The transformative paradigm has a different, explicitly ideological *raison d'être* of contributing to social change, and it takes a critical and political stance on knowledge production. This paradigm includes PAR as well as other liberatory approaches to research such as feminist, emancipatory, Marxist, "openly ideological",[54] and praxis-oriented research. Research, learning, and action are purposely combined. The central process is to identify and address local problems in ways that link them to larger structural issues.[55] Contributing to the empowerment of the research participants and the redistribution of societal power and control are principal aims. To achieve this, transformatory research uses social analysis and action to understand oppression and demystify expertise, acknowledges and uses popular knowledge, and creates new knowledge with research participants.[56] Research findings are continuously turned back to the participants in a process of joint analysis and assessment, and are used by the external researcher[57] to alter his/her own perspectives according to the logic of the data. PAR, one type of transformatory research, will be described in some detail in the next section (2.2).

13

Table 1

RESEARCH PARADIGMS		
POSITIVISM	**POST-POSITIVISM**	**TRANSFORMATORY**
Purpose		
causal explanations and laws for universal and reliable predictions to reduce undesirable occurrences or encourage desirable ones to occur more frequently.	understanding of patterns and meanings in lived experiences.	personal and social conscientization,empowerment, and transformation for political change to redress inequities and promote peace.
Nature of Reality (Ontology)		
a belief in a single reality independent of any observer, a mechanical explanation of cause and effect, and a belief that universal truths independent of time and place exist and can be discovered.	realities are multiple, socially constructed, ungoverned by universal laws, and are local and specific to the persons who live them.	realities are socially constructed, within a historic and political context; people are active subjects in lives of relationships of power.
Nature of Knowledge (Epistemology)		
a belief in a subject-object dualism--a researcher (the subject) investigates a phenomenon (the object) distanced from values or biases.	knowledge is a social, subjective construction, contextualized by language; the research findings are created by an inquiry process rather than being the result of the collection of external, already existing 'facts'; truth is not absolute.	ordinary people have the capacity to analyze reality and create knowledge; all peoples have an indigenous science and knowledge; fundamental human need drives inquiry; the researcher is part of the experience being studied; knowledge is holistic.
Methodology		
experimental designs that test specific hypotheses and free the object (that is, 'dependent variable') of its 'confounding' context; validity and reliability are important; a time frame is determined; people are 'objects' of study; theory and practice are not directly related.	hermeneutic/interpretive, and dialectic, in that it involves a constant comparison of differing interpretations; focuses on people's lived experiences located within a particular sociohistorical context.	praxis, that is, reflection-inquiry--reflection-action dialectic; participants direct research design and own the results; the researcher is part of the reality being researched, and the research findings are a creation of the inquiry process; emphasis on empowerment of participants through process and outcomes.
Methods		
those that produce quantitative data which is frequently dependent on complex statistics.	includes interviews, participant observation, case study, grounded theory; qualitative data produced; the researcher is an instrument.	varied--interviews, stories, drama, surveys; central is 'problem-posing' dialogue.
Knowledge Produced		
technical; instrumental.	interpretive; interactive.	personal; critical; spiritual.
Values Reflected		
human science is as predictable as physical science; status quo is maintained or manipulated; behaviour, health, and the environment are to be mastered.	human science cannot be predicted or reduced as physical science can; but human behaviour and health, and the environment may be better understood through interpretative study.	oppression can and should be challenged; respect, equality, commitment, and connection characterize relationships among research participants; reality is holistic.

A common purpose of all research is to create new knowledge. These three paradigms reflect a spectrum of thinking on the essence and production of knowledge rather than being completely immiscible approaches. While the assumptions and values of the paradigms are very different, in practice the distinction may blur.

The Limits of Positivism

The positivist approach to natural and medical sciences is indispensable for building bridges, channeling energy, isolating defective genes, and much more. In the social sciences, however, it has lacked that same kind of success for developing theories of explanatory or predictive power.[58] For all its contributions, Harman[59] argues that positivism is unable to deal adequately with many areas of human experience, such as complex instinctual behaviours, social organization and action, self-awareness, and creativity. In fact, Charles Lindblom, political scientist and professor emeritus at Yale, claims that, despite being practiced since ancient Greece, he "cannot identify a single social science finding or idea that is undeniably indispensable to any social task or effort."[60] Positivism is inadequate and inappropriate to study human processes for a number of reasons.

Our human world is created and described by language and culture, and all realities are interpreted through this filter and given meaning. For example, the concept of "peace" is understood in different ways. People in a war-torn country may experience peace during a holiday truce between factions. A terminally ill person may find peace when the arrangements of a will and funeral are in order. No explanatory law can determine which of these interpretations is *really* peace for the meaning is created during the course of human events. Cumulatively, these differences undermine the ability of positivism to explain or predict human behaviour other than in very general ways.[61]

The world described by modern science is devoid of the profound spiritual insights held by most peoples for thousands of years, and positivism has neglected those deep inner experiences which have guided and given meaning to all societies. For more holism and a greater connection with the

15

soul and spirit, it is necessary to look not into the science of physics but into the human mind and experience.[62]   In contemporary times, people are no longer accepting only our scientists' versions of reality but are seeking answers elsewhere, for example, Eastern religious and health philosophies.

The field of health promotion struggles to find the research paradigm that suits it best.   Because of its proximity to medicine, and the dominance of positivist medical research and disease prevention strategies, health promotion tries to fit into that paradigm, but it is an uneasy match.   The central concept of empowerment and the emphasis on ecological determinants of health do not lend themselves to double-blind, case control studies.   Labonte and Robertson[63] use an example to make this point: investigating empowerment and serum cholesterol with the same research paradigm is a fundamental error.   Paradigms appropriate to each are based on different ontological, epistemological, and methodological underpinnings.

Lewis[64] raises the question: To whom is health promotion accountable and for what?   If we were to comply with criteria of positivist research for funding and conducting our health promotion inquiries, we might win the debate within that scientific paradigm but lose the relationship with the communities whose health we want to foster.   Natural science positivist research has been outstandingly successful in pursuit of many important questions, but is limited in its ability to understand the human experience.

Rationale for Using PAR

The transformative paradigm and PAR are based on a certain world view of reality and knowledge that emerges from, but is different than, post-positivism.   Proponents of the transformative paradigm and PAR believe that the creation and depiction of knowledge influence our understanding of reality, and that those who control these processes wield considerable power. Yet power and influence are not fairly distributed and much in society is unjust.   Proponents also believe that research is not neutral and has a role to play in social justice.   Given that many people in our world are oppressed, research ought to serve to improve their lot.   The transformative paradigm is

a political one and is clearly not for everyone or for every situation, but it does have a place in social research and action for improved health and development. The decision to use PAR in this inquiry was based both on my own beliefs and interest in this approach, as well as its suitability for this particular initiative.

As discussed in the next section, PAR shares some features with the dominant research paradigms and others with the transforming methodologies yet nevertheless is distinct and unique.

2.2   Participatory   Action   Research

This section follows the rationale laid out in the previous section--research paradigms--for choosing participatory action research (PAR) as a primary focus of this study.   Here, PAR is described in terms of its origins, nature (qualities, stages, levels of knowledge, and the perspective of the Royal Society study), and elements and characteristics (dialogue, critical theory, values, power, dialectics and praxis, conscientization and *vivencia*).   The issues of reliability and validity in PAR are introduced.   Next are listed some common, general challenges, then those specific to the academic considering PAR.   Some expected results are given.   Finally, a brief overview is given of the Aboriginal experience with participatory inquiries, since this study was with an Aboriginal group.   Later, I use concepts from this section to describe (section 3.1) and analyze (sections 4.1 and 4.2) my experience with PAR.

2.2.1   The   Origins   of   PAR

The emergence of PAR in the 1970s was linked to challenges against traditional practices in economic development, adult education, and social science.[65 66 67]

Economic   Development

In the 1960s and 1970s, approaches to international aid and development, including Western research methodologies, were being criticized as

17

ineffective for reducing poverty and inequality and as contributing to a
rising economic and cultural dependency which exacerbated class
distinctions. For people in developing countries, conventional research
reflected a colonialist and neocolonialist dominance of research subjects
which distorted data,[68] resulted in an elitist monopoly of knowledge by
academe, and an ethnocentrism of Western science and technology.[69] As an
alternative, development specialists explored ways of increasing the
participation of the poor in development programs which would contribute
to their empowerment. PAR was developed as part of this movement,
primarily by researchers in developing countries[70] who pioneered "ways of
uncovering knowledge that work better in societies where interpretation of
reality must take second place to the changing of that reality."[71]

Adult Education

Traditional practices in adult education were also challenged in the 1970s,
both in the developing countries and the West. Paulo Freire's work in Brazil
in the late 1950s and early 1960s, approaching literacy through raising
political consciousness of peasants, formed the basis of his conceptual work,
Pedagogy of the Oppressed. Freire argued that teaching and research should
be based on dialogue with a community of oppressed people instead of
domination by experts. Through dialogue and collective action, people can
develop critical consciousness and act to liberate themselves. In the process,
they acquire the confidence, skills, and knowledge that they need to improve
their situation. A similar approach was advocated by a group of adult
educators, The Participatory Research Network, based in Toronto under the
leadership of Bud Hall and others, which provided important publications
and ideas for practitioners. Another major influence has been the
Highlander Center, in Tennessee, organized by Miles Horton and others in
the 1930s. The Highlander Center has inspired many participatory
researchers with its success in educating and empowering poor rural people,
for example, in the civil rights movement and in coal miners' struggles in
Appalachia.[72]

Challenges to positivist social science research have been especially important to the development of PAR in the developed countries. The "Frankfurt School" of Habermas, Adorno, Fromm, and others evolved the critical theory of society[73] and led to "action sociology." Critics of conventional positivist methods emphasized the links between knowledge and power, and argued that traditional scientific methods reinforce the domination of experts and the power of those who are White, male, and middle class. They proposed alternative paradigms, such as feminist science, which share many characteristics with PAR, for example, integrating research and theory with political action, and giving the people being studied more power over the research.[74]

Other participatory initiatives were being pioneered, concurrently, in various countries: the National Institute for Adult Education's evaluation of the British adult literacy campaign; Orifice and colleagues at the University of Naples in their investigations of community and district "awareness" of power and control; and, again, the Highlander Center which has used approaches similar to participatory research for years, most recently to deal with issues of land ownership and use.[75] Historically, PAR is related to Kurt Lewin's "action research," but differs substantially in that its goal is social transformation. PAR is more influenced by Paulo Freire's *Pedagogy of the Oppressed*,[76] in which research is focused "on promoting liberation and growth within a society assumed to be class divided and, hence, inequitable."[77] These combined countermovements refuted the epistemology and methodology of positivism, talked of paradigm shifts, and promoted research designs that were interactive, participatory, and grounded in the setting.[78]

2.2.2 The Nature of PAR

PAR has two fundamental purposes: to democratize knowledge and power through the research process,[79] and to reorient participants' perceptions of issues in ways that influence subsequent attitudes and behaviours.[80] To

these ends, PAR is used to transform both the socioeconomic context in which the research is conducted and the views of individuals taking part.

Fals-Borda[81] identifies three theoretical elements which enrich a research experience when using PAR, in contrast to positivism. **First**, PAR recognizes that people create, systematize, and institutionalize the knowledge of popular science, passing it on from one generation to the next. For example, most societies develop a system of folk medicine, much of it derived empirically, which becomes part of their popular knowledge. **Second**, the researcher-subject relationship is transformed and, despite their differences, the internal and external participants* interact "on an equal footing, each one offering . . . what he [sic] knows best."[82] The relationship works because of "mutual respect and shared commitment."[83] **Third**, independent and autonomous grassroots organization is promoted so that people can develop their own power to counteract that which is oppressing them.

In PAR, external researchers work with members of a community to provide more insight into community problems and take steps to resolve them. PAR may employ a variety of research methods from individual, in-depth interviews of personal experience, to surveys, to analysis of public documents. Most commonly, qualitative methods are chosen.

Qualities of PAR

Cancian and Armstead[84] identify five distinguishing qualities or principles of PAR: participation in the research by the people being studied; inclusion of popular knowledge, personal experiences, and other intuitive ways of knowing; a focus on empowerment and power relations; consciousness-raising and education of the participants; and political or collective action.

Participation

Participation in research may vary. Minimal participation could be asking people who are interviewed to read and comment on the transcripts of their interviews. Maximum participation is that which occurs when community members participate in and control all aspects of the research process, as

PAR aims to do. Participation also ranges from the pragmatic, which enriches the final research product with direct input from the researched, to the liberating such as in PAR which views participation as a tool for developing empowerment.[85] [86]

In PAR, participation is achieved primarily through dialogue among participants, internal and external, in all aspects of investigation and collective action. Using dialogue, the research produces factual, interpersonal, and critical knowledge, and is also a means by which people come to know themselves better as individuals and as a community.[87]

Popular Knowledge

The second feature of PAR is valuing popular knowledge and science, personal experience and feelings, and artistic and spiritual expressions as useful ways of knowing. To draw on popular knowledge, participatory researchers may use group discussions as well as photography, video, theatre, traditional tales, stories, and so on.[88] Positivist science dismisses knowledge derived from experience as biased and subjective. As Merrifield counters, though, "people living with a problem may know more about it than scientists who are far away and have not studied the issues. Community residents may be the first to know something is wrong, but the last to have their story accepted by scientists and officials."[89]

Empowerment and Power

A third feature of PAR is a focus on empowerment and power, which provides a political and moral framework for the research and implies both that the purpose of the research should be to equalize power and that research should serve the interests of the relatively powerless. Again, as in participation, there is a wide spectrum of positions that researchers take on empowerment and on ways to accomplish it,[90] but in PAR empowerment is a primary aim.

Empowerment may be defined as the process of increasing one's ability to choose, and one's capacity to define, analyze, and act upon one's problems.[91]

A way to understand empowerment is to find out how the phenomenon is actually experienced by those who feel they are, or are not, in control of their lives.[92]

The converse side of empowerment is oppression. Part of the phenomenon of oppression is that oppressed people are made to believe in the inevitability of socioeconomic inequalities in society. Their expectation is to continue in the lowest stratum of society. They think improving their lot will come only through their hard work or good luck as individuals, as the system itself is seen as unchangeable. People believe that they lack the capacities, the intellect, and the competence to produce knowledge for solving their own problems in their daily lives.[93] In the PAR process, people are given the opportunity to reflect on their situation and regain their capacities to analyze and critically examine their lives.[94]

The fourth and fifth features, which are related to empowerment, are raising the consciousness of participants and engaging in political or collective action to change the social situation.

Consciousness-Raising

Consciousness-raising occurs when individuals gain a fuller understanding of their own personal problems and of the larger forces that shape them such as the unequal distributions of power in the community and society. This may occur through group discussions and projects which attempt both to reduce participants' feelings of self-blame, unworthiness, and incompetence and to relate personal problems to more common forces in the community and society, such as racism and poverty. Many PAR initiatives have admitted limited success with achieving a critical consciousness about, for example, the influence of sexism on personal issues.[95] Kieffer[96] and Lord and McKillop Farlow[97] emphasize, however, that consciousness-raising is achieved when an issue affects an individual at a emotional level rather than an intellectual one only.

22

Political or Collective Action

Engaging in political or collective action involves challenging the existing power structure, which includes working against sexism, racism, classism, and other structural sources of inequality. Participatory researchers work with people to emphasize that their problems stem from inequality in the social structure, and that political action must be oriented towards structural change, not towards adjusting people to oppressive environments. PAR can contribute a small but important part to social change and transformation.[98]

To achieve change at a societal or personal level, however, is admittedly difficult and complex. Participatory researchers, therefore, emphasize the practicality and value of small changes, such as encouraging oppressed groups to generate their own knowledge and to appropriate existing knowledge that is useful to them. A realistic goal for sympathetic researchers is to organize research projects that create some change towards equality, however small, and to avoid projects that strengthen inequality.[99] Not everyone's participatory research will be seen as furthering "the revolution," although all PAR should be conscientizing.

Stages of PAR

There are various ways to describe the stages and steps of PAR, but any attempt at standardizing this process is done with caution so as not to pre-empt or pre-determine the course or direction that the research participants decide to take. Typically, though, there are four general stages of the PAR process:[100] orientation to a community; dialogue and negotiation with groups of people to clarify community problems and to raise consciousness; collective research; and collective action.

Ideally, a PAR project is initiated by a group of people who are seeking assistance in understanding and resolving a particular problem, such as a group of citizens concerned about pollution from a nearby factory. In reality, PAR projects more commonly are initiated by an external researcher who enters a community with a certain issue and/or purpose in mind, and establishes relationships and a research team.

23

Orientation

The community orientation stage can be the most bewildering and frustrating for a researcher if the request for inquiry has not come from the local people. This stage includes the steps of entering a community, experiencing its reality, getting to know the issues, building relationships, and developing interest regarding collective research.[101]

Dialogue and Negotiation

The dialogue stage involves researcher and community participants in dialogue to clarify their understandings about their situation, reach agreement on working together, identify specific questions to examine, negotiate who will be involved and how the research will proceed, and raise consciousness among all involved.

Collective Research

The research stage distinguishes PAR from community development. PAR has many features in common with community development: to conduct PAR is to do community development, but community development can be done without PAR. The formal "research" component in a PAR project may be large, but more typically it is small. The participation of community members in this stage ranges from overall management and operations, being trained and assisting in the data collection and analysis, to serving on a project advisory committee. "Ideally, the research produces changes in the power structure, and the process of doing the research also empowers participants as they learn that they can investigate and define reality themselves."[102]

Collective Action

The collective action stage involves addressing some of the problems identified through group dialogue and research.[103] Some projects result in major social changes and others produce small or transient changes. Notable

24

change often requires sustained resources and a vital community group, beyond that which supported a single PAR initiative. Tilakaratna[104] identifies four types of action initiated by groups in PAR:

- defensive--aimed at protecting existing sources and means of livelihood against encroachment by other more powerful interest groups;
- assertive--to claim rights to which they are entitled but which they do not automatically receive;
- constructive--such as self-help projects organized to satisfy a group's own needs;
- innovative or alternative--undertaking initiatives beyond the mainstream such as appropriate technology or cultural revitalization.

These stages of orientation, negotiation, research, and action appear linear, but in reality PAR works cyclically, with an overlay of the phases of reflection, inquiry, reflection, and action, and with aspects of the stages continuing during the inquiry. For example, some negotiation and renegotiation may extend throughout the research as issues, opinions, and participants change. Awareness, confidence, insight, and momentum from one cycle and stage stimulate and illuminate subsequent cycles in a journey of individual and community development and research.

relection   inquiry   reflection   action   reflection
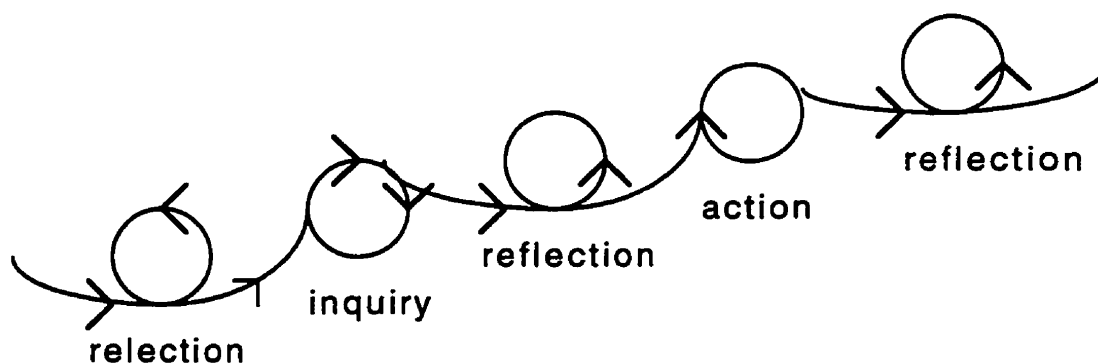
Levels of Knowledge

A further way of looking at PAR is in accordance with participants' level of knowledge. From personal communication with Arturo Ornelas, Smith[105] describes plotting the progress of PAR participants according to the levels of knowledge they achieve about forces that affect their lives: superficial, consequences, causes, and transcendence. More will be said about these levels in section 4.1.1.

The Royal Society of Canada's 1993 Study Report on Participatory Research in Health Promotion

The literature cited in this thesis describes PAR as it has evolved from principles of Freire's epistemology and social justice experiences around the world. This picture differs from an approach put forward recently on doing participatory research for health promotion.

In 1993, the Royal Society of Canada commissioned a study "to assess the status and promise of participatory research for knowledge development in health promotion."[106] The Society recognized, and wanted explicated, the central role participatory research could play in furthering the aims of health promotion in terms of people taking greater control over their own health. From my perspective, the study achieved several objectives:

- to bring participatory research in "from the margins" and set it at the table of dominant health sciences' research;
- to devise a set of guidelines for applicants and funders as a tool to assess the degree to which proposals adhere to the principles of employing participatory methods in health promotion research; and
- to recommend greater support from funding agencies for participatory research in health promotion.

Of concern, however, is that versions of what claim to be participatory research will be acceptable due to the latitude allowed in the guidelines, and that the true essence of PAR† --people's conscientizing research for socio-political change--will be appropriated by the current research community,

26

maintaining the *status quo*. Considering the financial resources that go into socio-health research, the power exercised in proposal selection, and the influence of research on knowledge developed and assimilated, appropriation of PAR is a risk. That is not to say that health promotion research using participatory methods should be dismissed as less than ideal and therefore not worthy, but it is important that the name and essence of PAR remain as they are without being co-opted by approaches which do not embody all its principles and aims.

2.2.3 Elements and Characteristics

There are a number of other aspects of PAR which deserve mention and will be listed here, with brief descriptions. "Problem-posing dialogue" is the main distinguishing feature of interviews in PAR. "Critical theory" is related to PAR and practised within it. PAR is value-based, and its "values" are made explicit. "Power" is a central concern of PAR. "Dialectics", "praxis", "conscientization," and *"vivencia"* are all features of PAR identified and explored especially by researchers in Latin America.

Dialogue

Typically, the interview style in PAR is based on Freire's concept of problem-posing dialogue, in which research participants are encouraged to critically reflect on and analyze parts of their lives that they might not ordinarily pay attention to or question;[107] in essence, to ask the question, "Why?" Dialogue, which means "an interactive process through which humans reflect and analyze, become able to name and understand their situation in the world, and hence to act on it and transform it"[108] is the methodological feature that distinguishes PAR from other social research.[109] Freire[110] clarifies that dialogue needs to be understood not as a way to challenge traditional research or teaching but as an essential part of knowing, which is understanding one's reality deeply enough to grasp the contradictions of how power influences our lives.

27

Critical Theory

Critical theory is an analytical critique comparing social reality and ideology, and focusing attention on the contradictions between them.[111] The goal of critical theory is "reducing asymmetrical power relationships,"[112] and it offers another epistemological foundation and theoretical focus for PAR. The practice of critical theory is seen in PAR through dialogue, the involvement of community members in creating critical knowledge, and the emphasis on human and moral values over technical knowledge.

Values

Smith identified three values on which PAR is based: capacity, equity, and commitment. She cautions that these will be tested throughout a PAR initiative "given the tensions inherent in any process of change."[113] "Capacity" refers to the quality of all people being able to think and work together for a better life.** Equity speaks to current and future knowledge, skills, and other resources being shared in ways that deliberately support fair distributions and structures. Regarding the third value, Fals-Borda specifies that "authentic commitment is required from external and internal participants"[114] at all times toward the shared goal of social transformation.

Power

PAR is about power and about acknowledging the role it plays at many levels in our lives, challenging the complacency and situation of those who wield a disproportionate amount, and championing those who do not have much by becoming partners in critical analysis and political action. PAR is about justice and the means of achieving more of it for a greater number of people through power-sharing.

Starhawk[115] describes a useful framework: *power-over, power-with*, and *power-from-within. Power-over* is the interpretation most commonly attributed to power whereby one player or group in a relationship determines the response of the other. Physical, economic, social, and cultural power are the most easily recognized forms, and it is the disparities

resulting from these influences that PAR and other social justice movements work to redress.

Power-with is the state in which relationships are equitable, respectful, and trusting, rather than exploitative, dominating, or oppressive. Power is shared and mutually influential among partners, and is dynamic and changeable depending on the circumstance. Proponents of PAR aim to induce a shift to *power-with* and *power-from-within* when working with participants who are on both sides of the power spectrum.

Power-from-within is inner power and "the power of truth."[116] It is both a spiritual state and the "light bulbs" of insight. For some, inner power is developed by a sense of coherence when life's experiences are "characterized by consistency, participation in shaping outcomes, and an underload-overload balance of stimuli."[117][118] For others, especially those for whom life is not predictable, inner power is a personal struggle and journey of enlightenment, awareness, and peace sought through experiences in religion, encounters with nature, cultural rituals and traditions, meditations, and humanitarian endeavors. Some believe,[119] as do I, that *power-with* is most attainable by individuals who are attending to and pursuing a path of *power-from-within*.

Dialectics and Praxis

In the Latin American discourse on oppression, liberation, and dialogical research, the term "dialectic" is used to describe a way of thinking beyond dualities. Rather than considering a concept in linear fashion as "either black or white," dialectics open up the options to various interpretations and relationships. Dialectics are "elements or forces acting in relation to each other. These can appear to be opposites and interact in tension (a tension dialectic) or can synergistically influence each other (a relational dialectic)."[120] Smith gives a useful example of a relational dialectic: In PAR, individuals make up a group; "a seemingly simple dialectic [occurs] between an individual (in the group) and the group itself. "[121] For progress to occur, each of these two elements--the individual and group--needs attention on its own, yet each influences and interacts with the other.

29

individual   group
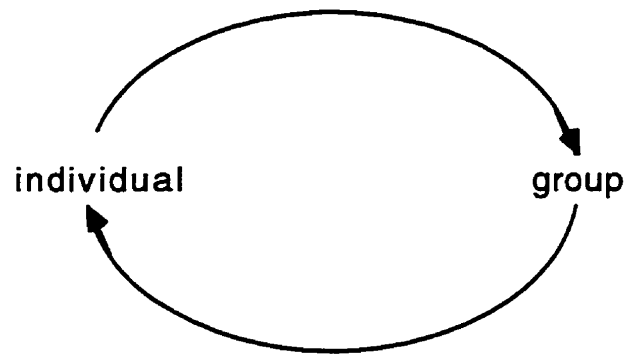
Examples of tension dialectics are found in section 4.1.

Praxis, the dialectic of reflection and action, was articulated by Freire and became one of the fundamental bases of PAR. Oppression, according to Freire, is "overwhelming control . . . [which] attempts to control thinking and action, leads women and men to adjust to the world, and inhibits their creative power."[122] In this context, praxis means that the intellectual discovery of the nature of oppression stimulates action in the struggle for liberation. That action is informed by serious reflection, and leads to consequences which are critically reflected upon. Hence, action is more than mere activism, and increasingly affects thinking. This praxis leads from a purely naive knowledge of reality to a higher level of knowledge which illuminates the causes of reality. Freire clarifies that to attempt to liberate the oppressed without their reflective participation is to treat them like objects who can be further manipulated. Furthermore, reflection without action "leads to informed passivity."[123] Yet, "separation from praxis" is "one of the most important structural prerequisites" of the academic research paradigm.[124] Discussions of research emphasize data collection and analysis but, as Kirby and McKenna point out, rarely the "responsibility to act on what is known. In fact, the opposite seems to be the case. Within the institutions of western education we are trained as spectators or commentators, to absorb experience, not to act on it. This disdain for the practical . . . has resulted in a kind of paralysis."[125]

Another meaning of praxis is the practice element of the theory and practice dialectic. What people know (their practice) requires theory to illuminate it. People emerge from their world of practice and conceptualize it, and in

30

doing so, they "can understand it and transform it"[126] through their actions which become further practice.

Conscientization and *Vivencia*

Conscientization, referred to earlier, under "Qualities" as consciousness-raising, is so fundamental to PAR that it will be described here, also, in Freirian language. Conscientization is the English translation of the Portuguese word *conscientização* popularized by Paulo Freire, which means "learning to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality."[127] In a later definition, Freire describes it as occurring when people "achieve a deepening awareness both of the socio-cultural reality that shapes their lives and of their capacity to transform that reality."[128] Freire maintains that rather than inciting people to fanaticism, conscientization "enrolls them in the search for self-affirmation."[129] Through conscientization, participants move from the status of "objects" to "subjects," from being known and acted upon to knowing and acting.

The concept of "experience" is basic to PAR and leads to conscientization. When we experience something, we intuitively capture its "essence; we feel, enjoy and understand it as reality."[130] In Spanish, this is called *vivencia*, which translated means "inner-life experience" or "happening." Yet for Fals-Borda the concept implies more: it is an experience "by which a person finds fulfillment for his/her being, not only in the workings of the inner self but in the osmotic otherness of nature and the wider society, and by learning not with the brain alone but also with the heart."[131] *Vivencia* and conscientization form relational dialectics with each other. For example, by working closely with the grandmothers and experiencing aspects of their lives, my awareness of racial and class oppression increased in ways I would not have achieved through theoretical study only.

2.2.4 Reliability and Validity

Reliability in positivist research requires that data gathering is done uniformly with all informants. In PAR, by contrast, it is essential that

31

informants, many of whom are co-researchers, understand why the research is being conducted, what each question means, and how to deepen a critical analysis of the data they are providing and gathering. Each interview experience is different, therefore, depending on the level of understanding of the informant and on the contribution made by the interviewer to enhance the clarity, completeness, and insight of the interview dialogue.

Comstock and Fox reflect on how knowledge created in PAR "is validated as appropriate, correct, or true,"[132] reviewing three related positions: the pragmatic, historical materialism, and critical. The pragmatic criterion refers to the knowledge created in research contributing to the solution of problems identified by research participants. Historical materialism gives validity to knowledge created that contributes to resolving problems of powerless people in general vis-à-vis domination. The critical criterion considers knowledge as valid if praxis is achieved: "theoretical insights generated by participatory research contribute to political action that reduces and eliminates oppression and gives power to the powerless and voices to the silent."[133]

2.2.5 Challenges

From the literature on PAR, three general challenges emerged that deserve mention, as well as others that pertain more specifically to those likely to face academics.

General Challenges

- To date, much PAR has been androcentric, led by male theorists and paying little attention to gender issues, although examples of a feminist influence are growing.[134]

Hall acknowledges this discourse bias, and credits Dorothy Smith and Patricia Maguire for their feminist influences on PAR. He concedes that the predominantly male researchers' "early assumption that women were automatically included in terms such as 'the people' or 'community' or the

'oppressed' has rendered them invisible in important ways."[135]   PAR theorists, while maintaining that "knowledge, which is socially constructed, is power, . . . [have] largely ignored the centrality of male power in that construction."[136]   This critique of PAR is central to its continued refinement as a transformatory paradigm for research.

- Because of its emphasis on unequal power relations, PAR is often used with oppressed groups who may not (i) have the capacity to devote to any endeavor which does not deal with basic survival needs, or (ii) be represented by an organized body with whom a researcher can work.

Various authors[137 138 139 140 141 142]   identified these two characteristics which have a strong influence on the ability of oppressed people to participate in research.

The third challenge places PAR initiatives within the social justice movement as a whole.

- If the analysis of the socioeconomic and political elements of the problem under study shows that they are, in fact, unchangeable, the analysis may heighten the research participants' frustration and dissatisfaction with the *status quo*, with little apparent resolution in sight.[143 144]

As Jackson[145] points out from his experience in participatory research with Aboriginal people, new knowledge and awareness are not enough to change policies and practices.

These three challenges, PAR's androcentricity, the oppressed's limited capacity to take on a research function, and the possibility of an unchangeable context are significant hurdles for PAR initiatives.

Challenges for Academics

For academics, there are many challenges to working with PAR.

- The time and commitment needed to develop community relationships, work according to a community's timetable or evolving focus, and attribute research and publications to collective ownership in PAR may be incongruent with the demands and time lines of academe for both the graduate student and faculty member.[146]

- Researchers typically expect to be in control of a research process in terms of complying with funding criteria, meeting proposed goals and objectives, working within a project time frame and budget, and keeping themselves personally detached from the research, none of which are consistent with research where control lies with community participants.

- Researchers using this methodology, despite some recent acceptance, still have to struggle for legitimacy within academic and research circles because PAR lies outside conventional research paradigms and its proposed design must be open-ended to respond to community direction.

- The hierarchical university structure is inconsistent with aspects of an egalitarian research methodology, and so the institution may have difficulty embracing this approach.

- The community group may find it hard to work with an academic researcher without being unduly influenced by his/her interests,[147] resources,[148] and skills,[149] and may defer to the expertise they perceive lies within the academic and not develop their own. Conversely, the academic researcher may struggle to assume an egalitarian, facilitating role with community groups without dominating the nature and process of the research.

- Internal power structures and struggles in communities that restrict participation may be poorly understood by the researcher and interfere with collective research.[150] [151] [152] † †

34

- Using PAR in the field of health promotion means working simultaneously in several different contradictory worlds: using the new language of health promotion, the old language of the traditional research establishments, the technical languages of different disciplines not usually associated with health, for example, urban planning, and the lay language of the street and community.[153]

2.2.6 Expected Results

In their "thinkpiece" paper, Hancock and Draper[154] list a number of health-promoting outcomes that PAR might achieve, including:

- Enriching data through the use of expertise in research subjects regarding problems studied.
- Raising, in the minds of the subjects, questions they might never otherwise ask themselves.
- Giving the powerless a voice and creating opportunities for that voice to be heard beyond their group.
- Establishing processes that link up people who never normally speak to each other.
- Moving from "power over" to "power with."
- Linking research with community action and change.
- Establishing ongoing processes of community change, activating/ mobilizing/empowering individuals and communities.
- Developing research skills in, and transferring other resources to, community people.
- Writing research results in different languages for different audiences.
- Taking information and results back to, and for ownership by, the community.

2.2.7 Aboriginal Experience

Because of its explicit challenge to oppression, PAR is most commonly used in disadvantaged communities. In fact, during the 1980s, it became, "in every respect, the way of working of the Aboriginal movement in Canada."[155] Jackson provides a comprehensive and informative overview of 20 years of PAR undertaken by Aboriginal people in Canada, starting in 1970. Beyond methodological lessons, Jackson points out that becoming familiar with specific Aboriginal examples and the overall PAR movement is valuable so that communities can identify potential partners for political alliances among social movements.

Galvanized by the federal government's 1969 assimilationist White Paper on Indian Policy,[156] Aboriginal leaders began to view research under their control as a strategy for political strength, establishing traditional land claims, and leading to political self-determination. Starting in the early 1970s with land use and occupancy studies, participatory research extended to water and sanitation, health, housing and social services by the end of that decade and through the next. Innovative methods were used, such as community research committees, study trips, and traditional songs, dances, and legends. Two unique methodological features that arose were that research findings were frequently fed into political hearings on land use and the environment, and the role of the outside, professional, nonparticipatory, non-Aboriginal researcher was explicitly criticized. Aboriginal studies initially employed exclusively qualitative methods but later they included sophisticated quantitative measures as well. Yet "one political lesson seems clear. New and accurate technical information is not enough to change the policies and services of the state . . . [which were] able to resist change through control over research dollars, bureaucratic delays, and other measures."[157]

There were a number of constraints on the Aboriginal PAR movement: experiences were fragmented, with little funding available to share research lessons among communities; research was controlled and directed by middle-class Aboriginal leaders; Aboriginal women did not participate proportionately in the process or outcomes of research; and "Aboriginal

participatory research continues to be held hostage to government funding."[158]

Progress has been made, however. For example, in the early 1980s, the Social Sciences and Humanities Research Council of Canada (SSHRC) officially supported "community-based and community-directed research in Aboriginal communities [and] . . . urged non-Aboriginal researchers to take their ethical and cultural direction from Aboriginal communities and to produce knowledge of use to these constituencies and to academic institutions."[159] In the first half of this decade, the federal government-appointed Royal Commission on Aboriginal Peoples held the most ambitious consultative research initiative to date, with a multiple-year mandate, a large budget, and four of the seven commissioners Aboriginal. The Commission held hearings across the country on issues of greatest concern to Aboriginal people; the final report was released November 21, 1996.

2.3   Health   Promotion

The second field of practice involved in this study is health promotion. As defined earlier, health promotion is the process of enabling individuals and communities to increase control over the determinants of health and thereby improve their health. Key concepts associated with both health promotion and PAR are "control," "powerlessness," and "empowerment." Below, I briefly outline the health promotion literature on these topics.

2.3.1   Control

A number of authors have examined the relationship between health and the concept of "control," and generally point to a higher status of health with increasing control over one's life.[160 161 162 163 164] The control that an individual experiences depends on an interaction between perceived and actual control. Perceived control refers to "the active belief that one has a choice among responses that are differentially effective in achieving the desired outcome."[165] Actual control is that which is determined by one's circumstances; people in certain situations objectively lack power in the political and economic system.[166]

37

Perceived control has been elaborated on by, among others, Rotter[167] in his seminal work on locus of control, Bandura[168][169] on self-efficacy, and Seligman[170] on learned helplessness. Perceived locus of control refers to generalized expectations for control of outcomes, ranging from internal-- contingent upon one's own behaviour, to external--contingent upon luck, chance, fortune, or misfortune. Self-efficacy, on the other hand, describes the belief that one is capable of engaging in a particular behaviour. Learned helplessness refers to a mental state resulting from experiencing consistent failures and/or chronically oppressive circumstances in which individuals, groups, or whole cultures may come to lack both perceived and actual control.[171]

Actual or objective control has been the more neglected side of the control construct in the health and psychological literature. Earlier concentration on perceived control had minimized the influence of a person's life circumstances and emphasized persuasion of individuals to increase their feelings of control, without necessarily changing their level of real control.[172] "Blaming the victim" was an outcome of people's apparent failure to exert control. However, the Lalonde health field [173] and World Health Organization health promotion concepts [174] have broadened the determinants of health beyond factors under the direct control of the individual. This emphasis on determinants speaks to "real control" and refers to "the extent to which individuals are able to make things happen the way they want."[175]

Green[176] describes the interaction between perceived and actual control as a downward spiral for loss of control. Life circumstances which provide few opportunities to exert control lead, over time, to feelings of helplessness in people. Their repeated failure to control events reinforces these feelings, and makes it less likely that they will try to take control in the future, even when they have a chance to do so. The spiral reverses to an upward direction in empowerment in which there are opportunities to succeed, small successes are achieved, and capabilities are recognized.

Control is also related to health by its interaction with self-esteem: if one respects and values oneself, one is more likely to look after oneself. Persons with high self-esteem may demonstrate this self-care in a variety of ways: adopting behaviours to prevent disease and promote health; resisting social pressures to act in ways risky to good health; coping constructively with stress and other health threats; and being less willing to tolerate dissonance between self-concept and unhealthy behaviours if undertaken.[177] [178]

2.3.2 Powerlessness

In a comprehensive article, Wallerstein reviews the health and social science research "relevant to both the role of powerlessness as a risk factor for disease, and the role of empowerment as a health-enhancing strategy."[179] Powerlessness is a concept which is defined as "lack of control over destiny[180] or "the expectancy held by the individual that his[/her] own behaviour cannot determine the occurrence of the outcomes...he[/she] seeks."[181] Aspects of powerlessness have been referred to as alienation, victim-blaming, learned helplessness, internalized oppression, and hidden injuries. Powerlessness, as a subjective or perceived phenomenon, is equated with external locus of control and learned helplessness. As an objective or actual phenomenon, it is a reality that people in certain situations do lack power in political and economic terms. There is a strong relationship between powerlessness and social class; powerlessness is experienced by those who are poor, low in the hierarchy, without control, and living in chronic hardship. From the research reviewed, Wallerstein suggests that experiencing powerlessness "is itself a broad risk factor that increases susceptibility to higher morbidity and mortality rates."[182]

Like control, the construct of powerlessness is formed by the continuous interaction between person and setting. Powerlessness "combines an attitude of self-blame, a sense of generalized distrust, a feeling of alienation from resources for social influence, an experience of disenfranchisement and economic vulnerability, and a sense of hopelessness in socio-political struggle."[183] Lord and McKillop Farlow[184] looked at, in both the literature and their own research, the professional social and health service solutions in the settings of respondents. They found that the professions often benefit

from keeping clients dependent and, in fact, perpetuate rather than alleviate the very conditions of victimization that need to be changed. In Freire's[185] analysis, powerlessness results from passive acceptance of oppressive cultural "givens," or surrender to a "culture of silence"; individuals assume the role of "object" acted upon by the environment, rather than "subject" in active engagement with the world.

2.3.3 Empowerment

Empowerment is another central concept of health promotion. In contrast to powerlessness, empowerment is "the participation of individuals and communities in a social action process that targets both individual and community change outcomes"[186] and is the process of increasing one's ability to choose and one's capacity to define, analyze, and act upon one's problems.[187] Kieffer describes empowerment as a long-term developmental process, "from socio-political illiteracy or 'infancy' to socio-political 'adulthood,'" in which participants attain a set of insights and abilities which he characterizes as "participatory competence."[188]

In moving along the developmental life-span of empowerment, there appear to be distinct and progressive phases of involvement as individuals gain insight and build skills toward participatory competence.[189] Disempowered people typically feel disinclined to become involved in social action; survival is a full-time occupation, and they are vulnerable to economic loss. Individuals do become involved, however, in response to a motivational trigger: a threat to their personal or family self-interests may result in an experienced sense of outrage or confrontation. The presence of a mentor is important to inspire, guide, and support the development of activism and provide a bridge for the individual with peers, self-help groups, or other community resources. Reflective experience and sufficient time are essential components for growth and maturation of individuals. Respondents in Kieffer's study[190] who saw themselves as being empowered described their experience not as "having more power" but rather as "feeling more powerful," that is, a transformation from the sense of self as helpless victim to acceptance of self as assertive and efficacious citizen.

40

Empowerment interventions emerge as a strategy for health promotion programs, directly addressing lack of control over destiny. "Through challenging social and physical risk factors in a collective setting, people gain a belief [that] they can control their worlds, a sense of their commonality, an ability to work together to acquire resources, and an actual transformation of socio-political conditions."[191]   Empowerment strategies may be thought of as preventive intervention because of the development of socio-political competencies in people: positive self-concept; critical analysis of their circumstances; and cultivation of individual and collective resources for action.[192]   Respondents in the study of Lord and McKillop Farlow[193] identified services which contributed to their empowerment as those which were personalized, interactive, and reduced dependency.

PAR, the focus of this inquiry, claims to empower participants, restoring their dignity through:

- their involvement with and control of the research agenda, process, and findings;
- their increasing critical awareness of the causes of the problems studied;
- promoting their development of grassroots organization; and
- establishing individual and community change as a planned outcome.

It remained, therefore, for this study to determine if PAR could function as an empowerment strategy for health promotion, reducing the risk of ill health due to powerlessness, and promoting health by increasing control of individuals and communities over their lives.

This concludes the chapter on literature pertinent to the focus of this thesis--research paradigms, PAR, health promotion, and related issues and concepts.   Further reference is made to the relevant literature throughout the document, and particularly in the discussions in the fourth chapter.

<u>Endnotes</u>:

*   Fals-Borda (1991:4) uses this typology of participants in PAR: those who are internal to the exploited classes and those who are external.

†   The study specifies in its report that it uses the term participatory research to encompass the term participatory action research. Whether or not the two terms were used synonymously in developmental years, the term participatory action research (PAR) has become the label for a unique approach to research within a transformatory paradigm.

* *   "Capacity" is used throughout this document to describe not only the ability of people to conduct their own research and take control of their lives, but also as the limited capacity of marginalized, disadvantaged people to act on this potential because of burdens and constraints they face for even basic survival.

††   Yet some researchers have found that PAR tends to "break down the local power hierarchies by developing a greater understanding and appreciation of the skills and commitments of various subclasses within the community."[194] [195]

3. Methodology

3.1 Methodology and Experience of Using PAR to Conduct the Health Assessment

This section is written in response to the secondary objective of my inquiry, to describe the experience of using PAR within a health promotion context. Here, I identify the participants of our research team, describe how we conducted the health assessment research, and discuss our experience using PAR in this assessment. To begin, a brief overview is given of the national context in which our work took place, then of the project which housed our research. Next, the research steps and chronology we followed are listed. Then the research is described in greater detail: orientation, dialogue and negotiation, participants, project programming, research design, consent, data collection, data analysis, information produced, action taken, and project closing.

Later, in section 4.2, "Discussion and Critical Reflections on Doing PAR," the inquiry's secondary objective is further addressed by analyzing our experience according to conceptualizations of PAR by other authors, and synthesizing and summarizing the tensions and lessons and accomplishments from the project and research. Although this inquiry was focussed on the health assessment part of the project, it was so intertwined with the rest of the project that often the description, analysis, and discussion do not distinguish the part from the whole.

To clarify, hereafter:

- the health assessment is referred to as the "research," the "health assessment," or the "health assessment research";[*]
- the methodology used to conduct the health assessment was participatory action research (PAR);

43

- the community health development project the research was conducted within is referred to as the "project" or the "grandmothers' project";
- the examination of the effects on the grandmothers of participating in the project and research (see sections 4.3 and 4.4) is referred to as "my research" since that was the principal question of my study, or as "the research on participation";
- the older Aboriginal women in the community who were the focus of the project and principal participants of the research are referred to as the "grandmothers";
- the "findings" refer either to my research or the experience of using PAR to conduct the health assessment, not to the results of the health assessment which are captured in a separate report, "Sharing Our Circle" (see Appendix A).

Purposely, this section is written in some detail. Interested but novice participatory researchers always want to know "how to" conduct this kind of inquiry. Yet they are deflected by theorists who maintain that each initiative is unique and a prescription is inappropriate. While this is true, the stories of journeys through a PAR experience are both interesting and illuminating and deserve to be accessible to others for the lessons learned. As well, readers' feedback to us who have made that journey may help to clarify questions that remain, and may pose options and interpretations we have not considered. In this spirit, I offer our story to share in common learning about PAR and its relationship to health promotion.

3.1.1 The Context

This section gives a brief introduction to the Aboriginal world in which the project and our research took place.

Your buildings tall, alien,
Cover the land;
Unfeeling concrete smothers,
windows glint
Like water to the sun.

44

No breezes blow
Through standing trees;
No scent of pine lightens my burden.

I see your buildings rising skyward,
majestic,
Over the trails where once men walked,
Significant rulers of this land
Who still hold the aboriginal title
In their hearts
By traditions known
Through eons of time.

Relearning our culture is not difficult,
Because those trails I remember
And their meaning I understand.

While skyscrapers hide the heavens,
They can fall.

Rita Joe[196]

In the five centuries since Europeans landed on Atlantic shores they have pursued aspirations at variance, and sometimes in direct conflict, with those of the Indian people who were here before them. As a result, the history of Indian-white relations has often been troubled. . . .

For three hundred years the European newcomers were driven by the search for fish and furs, the desire to explore the land, and the will to evangelize the native people. The Indians chose to tolerate the Europeans' fishing, to embrace the fur trade, to help with exploration, and to ignore, for the most part, attempts to harvest their souls.

But with the triumph of the agricultural frontier, the native people became an obstacle to the progress of the Europeans' plans. Cooperation gave way to coercion and, inevitably, coercion led to confrontation. Today, native organizations are building strength to pursue their land claims and other objectives. The aboriginal peoples are re-emerging as a strong force in Canadian life. . . [197]

As Miller points out in his book from which this quotation was taken, indigenous people in the Americas have a long history of being colonized. "The nature of a relationship between two peoples of different backgrounds is largely determined by the reasons they have for interacting."[198] In the case of the Europeans, their cultural and physical invasion was for purposes of conquest. Their explorers were claiming new world lands for their monarchs' military and economic expansion.

"Cultural invasion"[199] follows closely on geographic conquest. According to the language and analysis of Paulo Freire, "In order to dominate, the dominator has no choice but to deny true praxis to the people, [that is], deny them the right to say their own words and think their own thoughts."[200] The cultural invaders "penetrate the cultural context of another group, in disrespect for the latter's potentialities; they impose their own view of the world upon those they invade and inhibit the creativity of the invaded by curbing their expression."[201] Freire explains that conquest inauthenticates the culture of the invaded who begin to take on the invaders' values, standards, and goals. In order for the invasion to succeed, the invaded must believe they are intrinsically inferior and the invaders are therefore superior. The more the invaded are "alienated from the spirit of their own culture and from themselves, the more they want to be like the invaders . ."[202]

In 1969, the federal government's white paper on assimilation of Aboriginal people "stimulated many Aboriginal organizations to assert, once and for all, Aboriginal claim to their traditional land. By the early 1970s, comprehensive land use and occupancy studies were underway across Canada."[203] Attempts at assimilation continue today. Yet people of European and Aboriginal descent retain different world views which "explicitly and implicitly contain. . . their concerns, their doubts, their hopes, their way of seeing the leaders, their perceptions of themselves and of the oppressors, their religious beliefs . . ., their fatalism, their rebellious reactions."[204] Canadians of European descent tend to display pragmatic, do-it-yourself individualism while Aboriginal people strive to reclaim their traditional participatory democracy, cooperation, and altruism.

"Cultural synthesis,"[205] the opposite of invasion, recognizes and respects these differences, affirming the support each people gives to the other, and prohibiting the invasion of one by the other. Our contemporary White-Aboriginal relationship continues to look like cultural invasion while most parties recognize and espouse a need for synthesis. The participants of our research were largely a product of invasion, the

46

grandmothers from the invaded and I from the invaders. Our work together, our "cultural action,"[206] could either have served to reinforce that domination or contributed to the liberation of us all, and we intended the latter.

Through the terms of Treaty Six, signed between the Crown and the Plains Cree in 1876, First Nations people were to receive health care under provision of the "medicine chest" clause. A branch of the federal health department administered health services on reserves, but in the last decade has negotiated transfer of responsibility from the government to First Nations control. The urban First Nations and the Metis[†] people are not covered by this arrangement and their health care is under provincial jurisdiction, as it is for other residents of the province. An overall move to negotiate Aboriginal self-government has fundamental implications for the future nature and responsibility of health care services.

Two events occurred in the summer of 1990 that hailed a turning point in relations between Aboriginal people and the rest of Canada, at least for a time. The Meech Lake Accord, a new constitutional amendment proposed by the federal government to protect Quebec's status as a cultural entity, was blocked by Elijah Harper, an Aboriginal Manitoba legislator, who voted against it. Despite outrage from some camps, Harper "became an instant folk hero among his people"[207] and many others across the country who either supported special status for Quebec but objected to this amendment package or who objected to distinct designation at all.

Later that summer, to the shock and shame of many Canadians, the Oka crisis occurred, drawing international attention to the oppression of Aboriginal people in our country. Because of a dispute over traditional rights to land, heavily armed Mohawks, joined by Aboriginal activists from across the country, set up a series of blockades near Montreal that resulted in the shooting death of one police officer and a long and tense standoff between the Aboriginal people and the Canadian army. Via television, Canadians watched almost a full month of the disturbing confrontation between Mohawks and soldiers "standing nose to nose over

47

barbed wire. . . . Aboriginal issues became visceral and visible; Aboriginal rights were now on the public agenda in a big way."[208]

The opinions and positions of many Canadians shifted that summer, with new support and sympathy given by non-Aboriginal citizens for traditional land claims and self-government, and a renewed pride, resolve, and coalescence among Aboriginal people for their own rights and identity. Yet a poll conducted by the federal government in early 1996 and made public in July suggests that Canadians' attitudes towards Aboriginal people are hardening again: 40% of Canadians believed Aboriginal people have themselves to blame for their problems, compared with 35% two years ago; 47% said Aboriginals enjoyed a standard of living that was better than or equal to that of most Canadians --"a belief that isn't backed up by any economic indicator"--compared with 30% two years ago; 54% believed land claims by Aboriginal people were unreasonable, up from 46% two years ago. About 83% said they expected the living standards of Aboriginal people to stay the same or improve.[209]

Aboriginal people join other minority groups in a place in Canadian society that Kirby and McKenna call the "margins." When conducting research with certain groups,

> the margins refers to the context in which those who suffer injustice, inequality and exploitation live their lives. People find themselves on the margins not only in terms of resources. Knowledge production is also organized so that the views of a small group of people are presented as objective, as "The Truth." The majority of people are excluded from participating as either producers or participants in the creation of knowledge.[210]

In our research, the grandmothers lived their lives on the margins. Assessment of their health had to be done in relation to this context, the life patterns within, and how those patterns were sustained and controlled.[211]

Maguire described life on the margins for Aboriginal women who "suffer triple degradation: oppression based on race, gender, and class, both within the broader U.S culture and frequently within their own tribal cultures whether or not men in various tribes oppressed women prior to European contact . . . and that the status of Native American women within tribes has rapidly declined in recent years."[212]   In our health assessment research, besides race, gender, and class, age was a fourth variable in play.

The development of PAR, my interest in it, and the approach I took with this project and research were heavily influenced by the important work of Paulo Freire and other Latin American writers and activists.   They write about their own context, from a unique history, and in language and concepts specific to their struggles.   Yet the oppression of Aboriginal nations in Canada is parallel in many ways to that of the oppressed in Latin America, as are their goals of survival, dignity, justice, cultural preservation, self-reliance. Despite the similarities, the language and revolutionary paths to liberation that Freire writes about would not be familiar to most Aboriginal people in Canada.   Brant Castellano, a Mohawk woman and academic at Trent University, articulates a number of reasons why Aboriginal nations in Canada view their struggle differently than the oppressed of Latin America. "In practice among Native people in Canada, the language of liberation has less intuitive appeal and practical value"[213]: Canada's democratic system ostensibly encourages participation of all segments of society; Aboriginal people "deny intent to change fundamental structures of Canadian society"[214] because of some success in establishing unique status in the constitution; the possibility of destabilizing public institutions is minimal; and with the exception of the far north, Aboriginal people are a small minority, only two to three percent of the population, and are geographically dispersed in small settlements and urban neighborhoods.   The strategies and language of the struggle of marginalized people around the world differ, but the reality of oppression and the goal of justice and dignity are the same.

These few remarks on the context in which the project and research took place lead us to a description of the health promotion project in which

the participatory health assessment and my research on participation were embedded.

3.1.2 The Grandmothers' Project

Our health assessment, using PAR as the methodology, was done as part of a health promotion project for older Aboriginal** women originated by the local community clinic in a medium-sized city on the Canadian prairies. The proposal for the project had arisen out of an earlier clinic initiative on women's health. During those community consultations, Aboriginal women identified many unmet health needs among the grandmothers. Clinic staff wrote and submitted a project proposal to the federal government to address these needs. Over two years elapsed before funding was awarded. Catching everyone by surprise, 18 months of federal funding was granted in the fall of 1992. Upon completion of the first funded period, an additional 18 months was awarded which expired at the end of September 1995. When funding was first announced, neither the Aboriginal women initially consulted nor the clinic staff who wrote the proposal were around any longer. The new health promotion director was assigned this program to organize and manage. The project contract and accountability with the funders was established with the clinic as sponsoring agency. Recognizing the need to ground the project's development in the community of grandmothers, the director and other new staff of the project acted to form an advisory committee of older Aboriginal women to balance agency influence. This committee was a separate body from the grandmothers who later took part in general project programming.

Initially, the goals for this project were stated in terms of addressing common diseases. When the staff were hired and the advisory committee formed, the two groups agreed that the goals should be rewritten to shift from a disease to a health promotion focus. The first goal, however--to conduct a health assessment of older urban Aboriginal women--was never up for debate, other than to specify that it be done participatively. The funders and the director maintained that since this was a time-limited project, a health assessment would document the health profile of the

city's older Aboriginal women that could be used to get further support and programming in the future. The other three goals, as rewritten, were to support the grandmothers through health promotion programming, facilitate their leadership development, and build a network with other relevant services.

The tertiary hospital that housed the project was a very generous and supportive institution, offering office and meeting space and phone service without charge, accommodating many project needs. Moreover, the hospital was in the part of town where most of the grandmothers lived, and was known to almost all them from their own experience there as patients and visitors. However, because it was not an Aboriginal setting like the community centre in the downtown area, which could have been a site, we traded cultural congruency for convenience. Additionally, although the hospital was familiar, it was an old style building, foreboding and intimidating, and lent formality to our get-togethers, rather than providing a cozy, friendly atmosphere.

In theory, the project explicitly espoused the principles of self-reliance, control, participation, and empowerment in relation to the grandmothers, and in practice tried to stay true to them. In some fundamental ways it operated congruently with these principles and in other ways it did not, as will be described in this section and in 4.1 on critical reflections.

3.1.3   Research Steps, Chronology, and Stages

Following that introduction to the grandmothers' project, this section gives a brief overview of one aspect of the project--the health assessment conducted using PAR methodology. This description identifies the research steps undertaken, with approximate dates, and the themes interwoven throughout the length of the project. A more detailed discussion of the steps and themes is given later as part of other sections.

Our research was a component of the larger project and therefore was embedded in its origin and operations. There are various ways that the stages of our research could be described, one of which is breaking the

51

process into chronological steps, but with continuous themes threaded throughout the life of the project (see Figure 2 for summary). These themes were:

- Building trusting relationships: This was an ongoing task, in both project and research. Most of the grandmothers and staff, and I were new to one another, came from varied backgrounds, and had different agendas for our collaboration; furthermore, some were transient and/or irregular participants. As a result, we were continuously creating or strengthening our relationships and striving to create trust among ourselves.

- Forming a community of grandmothers: A major, ongoing purpose of the project and research was to form and build a sense of community among the diverse, divided, and isolated grandmothers.

- Developing interest in collective research: Trying to engender interest in conducting research felt like "swimming upstream" much of the time. The advisory committee, staff, and grandmothers were skeptical and reluctant, to varying degrees, because of their experiences and perceptions of research as exploitative and their preference for socializing rather than for taking on work-like initiatives.

- Collecting data indirectly: In my role of participant observer and formal note-taker, I gathered data continuously by documenting all activities and discussions as well as my own impressions, while steering the project towards particular health-related involvements.

- Taking action on findings: As needs and issues arose, the staff, grandmothers, and I responded with short-term solutions and/or longer-term involvements.

52

THE GRANDMOTHERS' PROJECT

Community at Large

Aboriginal Community

Aboriginal Grandmothers

Project Grandmothers

Project Goals
- **Health Assessment(PAR)**
- **Health Promotion Program**
- **Leadership Development**
- **Liaison with Others**

Advisory Committee

External Researcher

Research Associates

Project Staff

Community Clinic

Federal Government Funders
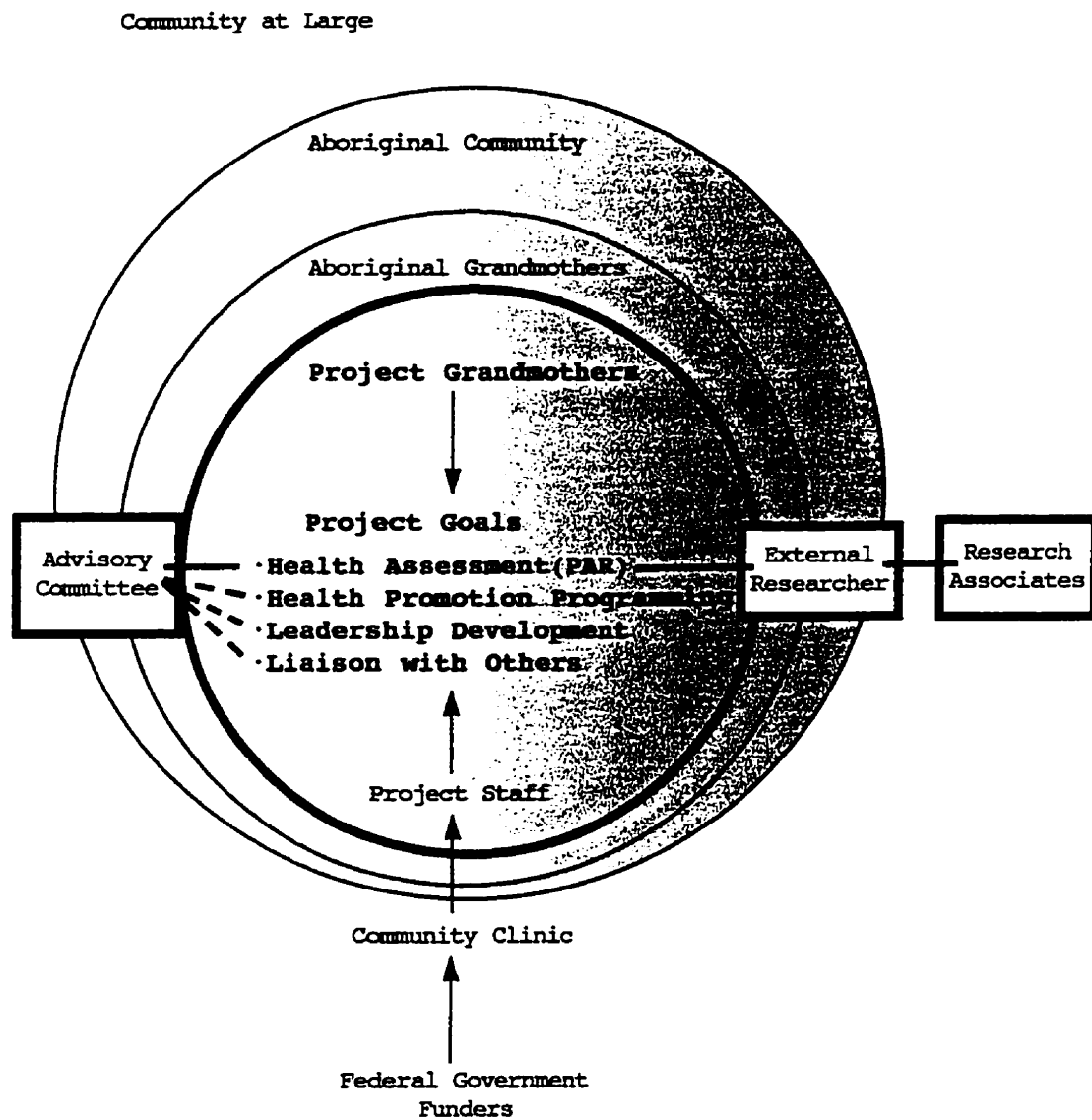
Figure 1   Organizational Chart

KEY

———— direct involvement

— — — advisory involvement

53
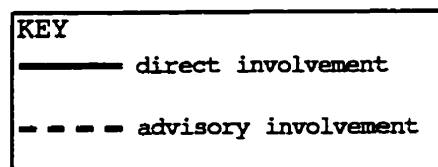
interwoven themes

```
---------- building  trusting  relationships  ----------
----------- forming  a  community  of  grandmothers  ----------
---------- developing  interest  in  collective  research  ----------
          ---------- collecting  data  indirectly  ----------
          ---------- taking  action  on  findings  ----------
```

#1	#2	#3	#4	#5	#6	#7	#8	#9	#10
project starts	project organized	research negotiated	project orientation ongoing	research plan defined	research renegotiated research plan redefined	direct data collection and validation done	data analyzed and assessment framework drafted	report written, revised, accepted, and published	research findings used[2]
									late/95 - early/96; pending
staff[1]	staff advs cmte	staff advs cmte ER	GMs staff advs cmte ER	advs cmte ER staff	GMs ER staff res assocs	GMs ER staff res assocs	GMs ER staff	GMs ER staff	

Figure 2   **Steps and chronology of participatory health assessment research**

---

[1]   This row identifies the people involved in each step: staff, grandmothers (GMs), advisory committee (advs cmte), external researcher (ER), research associates (res assocs).

[2]   Project funding ended, September 30, 1995. The grandmothers, staff, and I continued to meet informally and irregularly thereafter.

The chronology and steps of the research are as follows:

date	steps
October 1992	**Project started**

Earlier community consultations of the local community clinic (1989-90) had identified unmet health needs of older, urban Aboriginal women. Funding was awarded for a health promotion project that included a health assessment.

late 1992 - early 1993	**Project organized**

The new project was organized: staff hired, advisory committee established, project publicized to the community, home visits began, and a weekly group started of grandmothers from the community.

late 1992 - early 1993	**Research negotiated**

To staff and advisory committee, the project director confirmed the health assessment as part of the project. With them, I confirmed my role as external researcher for the assessment.

late 1992 - late 1993	**Project orientation**

The advisory committee, staff, grandmothers, and I were oriented to the project and each other over the first year through our joint involvement in a variety of tasks, some specifically for the health assessment and others on general project activities.

March 1993 - October 1993	**Research plan defined**

Advisory committee, staff, and I became the research core group, and developed the initial research design at three research planning workshops. Advisory committee dissolves in October.

October 1993 -   **Research renegotiated and research plan**
early 1994   **redefined**
The grandmothers replaced the advisory committee as participants on an expanded renamed research team. The research associates (described later in 3.1.4) were hired. As the new team, we renegotiated intent and purpose, and redefined the research plan.

December 1993 -   **Direct data collection and validation done**
late 1994
The staff, research associates, and I conducted individual interviews with grandmothers of the project and other grandmothers less involved. We conducted group interviews and member checks by taking loosely organized data from individual interviews back to the grandmothers at weekly get-togethers to be corrected, supplemented, clarified, and validated.
††

late 1994 -   **Data analyzed and assessment framework**
early 1995   **drafted**
Initially this was done by me, then reviewed and revised many times by the   grandmothers.

January 1995 -   **Report written, revised, accepted, and**
June 1995   **published**
"Sharing our Health Circle" report was compiled by me from the grandmothers' words. Repeated review and revision of the report were done by the grandmothers, staff, and me, individually and in group.

late 1995 to   **Research findings used**
present
Findings were used by the grandmothers, for their personal information, and as the resource document for a workshop, *Sharing Our Values*, held a year after project closure. Findings were used by staff at workshops and to communicate the project's work to relevant agencies.

September 1996   **Project ends**

Funding expires. Grandmothers, staff, and I continue to meet on an informal, infrequent basis thereafter.

While this was the path and sequence of our research, it must be stressed that each PAR initiative is unique because it is responsive to the particular context, composition of participants, and research question. Fals-Borda even cautions against imitating or replicating successful techniques. He argues that to be culturally appropriate in each situation, it is "preferable to undertake new actions every time, depending on the specific conditions and circumstances of each experience... [with] freedom to explore and recreate in these conditions."[215] Kirby and McKenna added that "as different people use the method they contribute to the way in which it is developed. . . . [It is a] method in process; it is continually unfolding."[216]

As described in these stages and steps, our process had similarities to aspects of others' models of PAR. [217][218] [219] [220] [221] [222] Yet there were also differences which demonstrate that despite common elements, each initiative is unique. For example:

- Our health assessment research was conducted with a group that itself was only being formed at the time.
- The research was not identified and requested by people in a problem situation, but was predetermined by planners and funders.
- A participatory methodology was advocated by the funders and project director, and PAR was proposed by me, the external researcher, looking for a field opportunity to learn more about it.
- The research was designed and carried out by two different participant groups--the advisory committee and the grandmothers--although both were composed of older Aboriginal women.
- Problem-posing techniques and dialogue to describe and analyze problems and link them to the broader context were only moderately successful with the advisory committee and somewhat

less so with the grandmothers, although a social analysis did develop gradually.

- Modest social and political action was undertaken but less was continued and only in conjunction with other groups who remained funded and established.

This concludes the overview of the project and chronology of the health assessment research steps and leads into the next, more detailed description of the research stages, the four participant groups, the activities of the project as a whole, and the steps involved in carrying out the health assessment.

3.1.4 Detailed Research and Programming

Dialogue and Negotiation

In this section, I describe in more detail the dialogue and negotiation process undertaken with each of three groups--the staff, advisory committee, and grandmothers--to conduct PAR in this project; the groups are introduced in the order that I met them. Dialogue and negotiation are described prior to orientation, the first of the stages listed in the literature by Cancian and Armstead[223] and in section 2.2.2, because in our work that stage preceded orientation, then became blended with it.

In late November 1992, through a contact suggested by a member of my doctoral committee, I asked to meet with the community clinic's health promotion director, who had responsibility for the newly funded grandmothers' project, and with the other two recently hired staff (a full-time coordinator and a part-time outreach worker), both Aboriginal women. We discussed the project's plan to conduct a health assessment, the staff's belief that it should be done "with" the grandmothers rather than "on" them, and my interest in finding a community project for the research phase of my doctoral studies on participatory action research and health promotion.

The director was newly hired for the recently created health promotion department of the clinic. Because of her personal and professional philosophy, she was committed to eliciting the active participation of the grandmothers in the health assessment. My interest in working with the project was welcomed by her because she could devolve responsibility for one part of the project and be assured it would be done well since it was part of my academic program.

To the other two staff members I was unknown other than being a White, middle-class academic who was to do the health assessment portion of the project. Implicitly, therefore, I was suspect, because I represented research and the dominant culture, both seen as exploitative. Ostensibly, negotiated acceptance by the director included the staff, but informally and indirectly I negotiated with them for about six months before sensing acceptance.

The day after my first meeting with the staff, the director telephoned me with the staff's endorsement to join the project if the advisory committee agreed. The staff had invited five Aboriginal women to form a committee to help launch and guide the project. The new advisory committee and staff held two meetings in early December 1992 and early January 1993 to clarify roles and responsibilities. They then set a special meeting at the end of January to discuss my inclusion in the project for the health assessment.

At this late January meeting, after a brief introduction by the director, the session was turned over to me. By showing photographs of my family and explaining my personal and professional background, I introduced myself. Then, I explained my beliefs on health and illness by telling a story of a woman whose baby becomes sick and dies. Together, we analyzed the factors which determined that family's state of health by using a visual technique of building a chain of causes and consequences. Through this exercise, I presented my views that emphasize the socioeconomic determinants of health and illness. Next, I gave a brief introduction to PAR, community development, and health assessment. Finally, I proposed that the advisory committee, staff, and I work together

59

as the research core group and initial participants of the health assessment, and that they be subjects of my research on the effects of participation on them. As we broke up, each of the advisory committee members gave her consent to have me join them in the project.

When meeting the advisory committee for the first time, I felt it essential to explain the value base of PAR and my own views of health and research. That way, the committee could make an informed decision about my participation and the explanation would also establish the philosophy of the research that we would do together if they chose to accept me. They were a polite group who appeared interested in and sympathetic to what I presented, and agreeably but not enthusiastically consented to have me join them. They did no questioning, probing, or challenging, however. I did not really know, therefore, whether they understood what I was proposing, felt they had a right to refuse my inclusion, or even wanted to do a health assessment at all.

I conclude now that if the advisory committee had felt it had the opportunity and authority to exclude the health assessment, it would have done so. The members' rationale, as they said from time to time, was that they already knew what the problems were--poverty and poor housing, isolation and lack of transportation, fragile health and need for healing, family addictions and other dysfunction--and that the project's efforts would be better spent addressing these issues than doing more study. This was never said to me directly, but it is the sense that I developed from some of committee members' comments and their limited involvement with the assessment. More examination of this issue follows in later sections (4.1 and 4.2).

At that stage, I did not foresee negotiating with the grandmothers, who would be the focus of the whole project, until the advisory committee, staff, and I had reached an understanding on how to conduct the health assessment and who would be involved beyond ourselves. The grandmothers had not yet become part of the project, but would be active research participants at some future time, I hoped. When the grandmothers started meeting together, the staff explicitly requested that

I say nothing to them about research because that realization might deter them from participating in the project as a whole. Only later, when group identity and trust were built up, would the staff risk introducing the idea of research.

In my dialogue and negotiations, with the exception of the project director, I felt the onus was on me to interest, persuade, and engage the three groups (advisory committee, staff, and grandmothers) in joint research. It was *my* objective to learn about PAR and *my* belief that research could be both useful and empowering.

Orientation

After negotiating "permission" to do the health assessment with those who were to be part of the research team, I involved myself in the project overall to become "grounded" in the context and oriented to the project and its participants. It was important for me to develop an understanding of the lives of the participating women and to become known to and trusted by them. I attended the monthly advisory committee meetings, helped with the weekly get-togethers and other activities of the grandmothers (described in detail under "Programming"), planned programming with staff and, after some months of becoming known, began to visit grandmothers in their homes.

With the advisory committee, my time was focussed on the health assessment from the beginning, as I felt a sense of urgency about getting it organized and started while we had resources and an opportunity to hold the planning workshops. Yet only when I did individual interviews with advisory committee members in the summer of 1993 and follow-up visits with them in the fall did I begin to establish a closer relationship with each of them. I see now that we might have been more successful in part if this sequence had been reversed, doing individual interviews first to establish a relationship, then coming together as a group; or if the two approaches were done concurrently. I would have got to know them personally either before or at the same time as we attempted to launch the research. In Brydon-Miller's participatory research she found that her

"face-to-face interviews contributed more to the development and subsequent success of the project"[224] than perhaps anything else.

The staff and I got to know one another gradually through our mutual work with the grandmothers in programming activities and in project planning. The relationship between the director and me was readily developed and cordial because we had some common background, interests, and values. The coordinator viewed me with caution for the first six months until we attended a conference together on PAR where, from a personal story that I related, she saw a very human side of me and gave me her friendship and respect from that time forward. The outreach worker and I built up an easy relationship around our common work with the grandmothers.

With the grandmothers, since they were not part of the research team initially, I had time to build up a relationship and serve different functions in their group before we became partners in research. Much of my first year with them was devoted to getting past our differences and becoming friends and colleagues based on familiarity, trust, and emerging communalities, as they did also with each other. As a nurse, I was easily categorized by them and given respect for my profession. To a large extent, I set my formal agenda aside and responded to their interests and needs as a woman, friend, and nurse. This time with the grandmothers also provided an opportunity for gradually introducing and considering the concept, value, and meaning of a health assessment.

As Maguire, too, found, "developing caring relationships with people, oppressed or otherwise, takes time for meaningful involvement in each other's lives and nurturance of the relationship. . . . Likewise, it takes that same time and meaningful involvement for those participating in the project to develop relationships with each other, not simply the researcher."[225]

These activities concluded the initial orientation. Yet orientation continued throughout the project as new grandmothers and the research

associates joined in, and new questions and issues arose about the research that needed addressing.

Research Participants

This section identifies those involved in the health assessment--advisory committee, grandmothers, staff, and research associates (to be introduced later in this section)--and describes their role and function (my external researcher experience is found in section 4.2), and also the "reflections committee" which provided me with peer support, checks, and guidance. Listed below are terms I used to designate individuals and groups associated with the research.

Designations

core group: advisory committee, staff, and external researcher

external researcher (ER): someone from outside the group who guides, facilitates, and is a resource to the research

participants or co-researchers: individuals actively involved in organizing and conducting the research and usually providing data

team: core group renamed with inclusion of grandmothers and research associates after dissolution of advisory committee

reflections committee: a group of individuals who provided ER peer debriefing on how to conduct PAR and on analysis of the participation data

sponsor: the executing agency--the community clinic

informant: an individual providing data

To clarify, the health assessment used PAR as the methodology and was initially to be conducted by the advisory committee and me, with staff

assistance, and later to encompass grandmothers who became part of the general project programming. With the dissolution of the advisory committee in October, 1993, the grandmothers, who by then were well established in the project, became the principal participants of the health assessment with me, with continued staff assistance; two research associates were hired the next month.

Fals-Borda identifies only two types of participants in PAR: those who are internal to the exploited classes and those who are external. In our health assessment, the members of the advisory committee and the grandmothers were internal; the project director and I were external. The research associates, because of their race, class, and culture belonged to the internal; the other staff bridged both worlds--the coordinator fitting more into the internal category and the non-Aboriginal outreach worker, the external. Notwithstanding, both the internal and external types of "animators or agents of change . . . are unified in one sole purpose--that of achieving the shared goals of social transformation."[226] [227] [228] All participants contributed their own expertise thereby producing a more balanced, whole picture of reality than one group could alone.

Advisory Committee

The advisory committee was the principal group with whom I was to conduct the health assessment. During the time it was together, the committee served the project well at discrete times--a meeting, workshop, or special function. The terms of reference for the advisory committee included: giving guidance on Native traditions and programming priorities; supporting and promoting the project in the wider community; and working with the health assessment--data collection, analysis, and interpretation. In keeping with this mandate, members contributed ideas and acted as a sounding board for the staff regarding initial programming, gave some profile to the project in the community, developed a preliminary research design that gave form to the health assessment, and lent initial guidance and cultural wisdom to the direction and priorities of the project.

In the beginning, the advisory committee was composed of five women who were First Nations or Metis, and were nominated by the staff and well-respected individuals in the Aboriginal community. Four were grandmothers themselves, ranging in age from the mid-forties to early sixties; the other was in her mid-thirties but invited because of her health and nursing background. They were all well known and had years of activist experience in Aboriginal issues. One, considered by some to be an elder, conducted a few ceremonies for the group. Meetings were held every month for the committee to advise the project on its general programming; the health assessment was addressed at special workshops to provide more time and attention. The advisory committee had direct contact with the staff and me, but little contact with the grandmothers of the project programming unless they attended the weekly get-togethers or other functions which they did not often do.

Although all members of the advisory committee expressed satisfaction that finally there was a project for urban Aboriginal grandmothers, only a few of them participated regularly. Most were busy women with family or work demands who did not devote much time or energy to the project. Only one attended many of our other functions including the grandmothers' weekly get-togethers. Because of the limited involvement of most members and its short life, the committee did not provide ongoing support and guidance for the project or serve as the core of the health assessment research team. The advisory committee member considered to be an elder attended the least. The absence of an active elder left the committee and the project only minimally grounded in Aboriginal traditions. A year after the project's completion, the coordinator gave me her assessment of what we could have done better. Having a resident elder, not only for the advisory committee and health assessment but the project as a whole, was her top priority.

After the first few months, when the attendance of the advisory committee members at the monthly meetings became irregular, the director suggested enlarging the committee by inviting one of the grandmothers from the regular project programming. By the summer,

with attendance still low, a further three grandmothers from the project were invited, making nine in all.

According to their terms of reference, the committee's role was advisory, not legislative, and not executive except for the health assessment. The project was clearly under the administration of the clinic, an agency not well known to these women, and thus it likely felt alien to them. The committee members had some responsibility for the success of the project, with high hopes for their involvement by staff and me, but they did not have the authority to control it. This "hands off" role accounted, at least in part, for the lack of commitment to and ownership of the project by most of the committee members. This alienation was exhibited in irregular attendance at meetings, infrequent participation in other activities, and distrust of the financial management. A more "hands on" role might have brought its own set of difficulties, with jockeying for control among members of the committee, between the committee and the grandmothers, or between the committee and the clinic which was accountable to the funders. On the other hand, more control by the committee might have fostered more engagement by the greater Aboriginal community and individual committee members in the goals of the project.

When I joined the project, the advisory committee was to be the core of the research team for the health assessment. The committee was to take a more active role with the assessment, as co-researchers and informants, than with the rest of the project. The opportunities for this role and their contribution were to be developed at the assessment planning workshops held over the first year (detailed later under "Research Design"). At these workshops, we moved methodically through all the fundamental steps of participatory research, clarifying assumptions, exploring purpose, and so on, building up to the research design. The members may have found that such an approach obscured "the forest for the trees" and seemed like tedious work for a group that wanted action. Yet because some of them had been involved in research projects themselves, they were generally more comfortable with research than were the grandmothers. Still, they were critical of it as too often being useless and exploitative.

The committee had a few incidents of open conflict but did not establish a process of resolution. For example, one member objected to being called Aboriginal and wanted to be referred to by her specific First Nations designation, and wanted the distinction made between First Nations and Metis people. Other researchers have written of internal power struggles in communities that interfere with members' participation in research and other activities.[229] From its inception, the grandmothers' project stated clearly that it was to cover all Aboriginal women, and the advisory committee had agreed to that.*** Yet seven months after the committee started meeting, this challenge arose. Word of the dispute spread to the Aboriginal community at large, furthering the conflict.

The women of the committee were activists in their own right and, accustomed to confrontation, they brought those traits into the committee. Both the director and I, as non-Aboriginals, tried to play a background role with the committee whenever possible. Furthermore, we did not know how to appropriately mediate conflict with these two cultural groups. In retrospect, I see that one of us as an outsider could have tried to play a mediating role. It might have been successful, or it might have resulted in one of us being blamed for the conflict.

The advisory committee stayed together until mid-October 1993. At this time, at the end of our third health assessment workshop, one of the members proposed that the committee was no longer needed. She gave two reasons: having an advisory group was the White, not Aboriginal, way of operating; and the project was mature enough now with a solid core of grandmothers in the project programming to guide the project. The others present agreed with this proposal and her rationale. The director telephoned the members not present at the meeting and consensus was reached that the committee would be dissolved. The director encouraged the committee members to integrate themselves thereafter into the general programming of the project.

The committee member who was most regular and involved was the one who finally suggested its dissolution. This was partly due to frustration

over the committee's transient composition, tensions and conflicts, and lack of real authority, and partly in appreciation of the ability of the project grandmothers to direct activities themselves. Moreover, she said that guidance traditionally comes from the more elderly, and the grandmothers in the general project programming were older than the remaining participating advisory committee members.

The implication of the dissolution for the health assessment research was that the committee members were no longer functioning as co-researchers, and much of the last year of developmental work on the health assessment was in jeopardy.

Staff

The staff also worked with the advisory committee and me on the health assessment. Within the first two months of the project, in late 1992, staff changed when the full-time coordinator left her position with no explanation, leaving only the part-time outreach worker. A search for another staff member was conducted. No suitable Aboriginal candidate was found, despite assistance by the advisory committee. The outreach worker, who was fluent in Cree, the principal Aboriginal language of this area, was selected by the director to move into the coordinator position. A new woman was hired in January 1993 as part-time outreach worker. She was not Aboriginal but, through her Metis husband, was well known in the Aboriginal community. The director, these two staff members, and I worked closely together over the next 2.5 years of the project, not only on the health assessment, but on project programming in general. We were all about the same age--mid-forties to fifty, and at the same stage in our lives--married with children in their late adolescence or early adulthood; only the coordinator had grandchildren.

The staffing situation showed both the difficulty of operating an Aboriginal program from a non-Aboriginal institution and the differences within the Aboriginal community. When the first coordinator left, the project's inability to hire another Aboriginal woman showed the lack of connection the clinic had to the Aboriginal

community, despite contacts through the advisory committee. Beyond that issue, there was an urgency to hire someone and get the programming going since the funding for this project had to be used within a short time frame. It would have been preferable to find a second Aboriginal person; hiring a non-Aboriginal was a compromise.

Our coordinator was a Metis woman and, despite everyone's explicit agreement that the project was for all older women of Aboriginal ancestry, divisions occurred. The staff team would have been better balanced with the original situation of one First Nations woman and one Metis. The coordinator, however, managed to ground and guide the project through most differences. To a large extent, she had good relationships with the grandmothers, advisory committee, community agencies, project director, and me.

Six months into programming with the grandmothers, the staff felt the grandmothers had developed a sense of group cohesion and affiliation with the project. At my urging and with their own increased ease with the grandmothers and research, the staff started introducing the concept and language of health assessment research, and my role in it, and inviting the grandmothers to participate in it with the advisory committee. After the dissolution of the committee a few months later, the staff and I began to speak more often to the grandmothers about doing the health assessment research together, and deliberately using those words to increase comfort with the language and concept.

Whereas we were all on the research team, the role of the staff, and later that of the research associates, was more like mine--executive. The roles of the advisory committee and grandmothers, however, were both legislative and as subjects. The staff were actively involved and supportive of the health assessment in a variety of ways: strategizing on design and operation; describing the assessment to the grandmothers as part of the project (starting the second half of the first year); conducting some interviews; contributing to analysis; assisting with the employment, training, and supervision of the research associates; reviewing report drafts; and disseminating the report.

Grandmothers

Although the grandmothers were the primary focus of the project as a whole, sequentially they were the third group to join me in the health assessment, adding to the staff and advisory committee, and eventually replacing the latter.

The 1991 Statistics Canada survey estimated that there were 295 women, aged 55 and over, of Aboriginal ancestry in our city. According to our staff, advisory committee, and grandmothers, and substantiated by a 1988 survey of Aboriginal off-reserve elderly,[230] most Aboriginal seniors who live in urban areas have moved from their home reserves or small communities to the city to be with their children and grandchildren and also to be closer to health care services.

Finding and attracting grandmothers in the city to participate in the project was done principally by the staff both through agency contacts and word of mouth. Recruiting grandmothers was an ongoing, core function of staff, advisory committee, and participating grandmothers. Initially the staff went to the inner-city elementary schools and sent home notices with all the children to invite their grandmothers. The staff also went to health care facilities, social agencies, churches, and Aboriginal organizations, describing the project, and leaving brochures and referral forms. Later, most grandmothers were found through personal contacts.

Once grandmothers were suggested to the staff and were contacted by them, retaining them in the programming was an ongoing effort. The project was operating in ways that were foreign to many of them:

- in the city, a new environment;
- in a group other than family or close friends;
- in English with Cree translation;
- with other types of people, for example, our guest speakers;
- meeting in a large institution;

- using traditions known to some but not to others;
- using structured meetings and educationals;
- taking part in new recreational activities;
- sitting on external committees; and
- going to public events representing the project.

Their capacity and participation were limited by these unfamiliar factors, by their physical and mental health constraints, and by family responsibilities. The staff's and my expectations and encouragement of the grandmothers continually challenged, tested, and stretched their ability to assume control of or contribute to project activities.

Despite the barriers, within a year the project had a list of 26 grandmothers who participated in activities on a semi-regular basis; the turnout at our regular Tuesday morning get-together was anywhere from 4 to 15. The ages ranged from approximately 40 to 70 years. The grandmothers were either First Nations, Metis, or mixed, and predominantly Cree. Even though most of these grandmothers may have known of one another through common friends or relatives, many had not socialized together during their time in the city. When they came together in our project, they spoke to each other in both Cree and English. Of these grandmothers, about 12 were regular and involved enough during the active phase of the health assessment to be considered part of the research team as co-researchers.

A second list of almost 40 more grandmothers included those who were known to staff but whom we saw less frequently. The staff and I visited those unable to come to the group activities in their home and/or, occasionally, arranged small kitchen meetings of a few grandmothers visiting together. About half of these were interviewed for the health assessment; consequently, they were subjects and informants of the research but were not active in other roles and therefore not considered co-researchers.

The grandmothers who were active with the project tended to be those who were less socially isolated, comfortable in both cultures, and able to

manage the demands on their time and energy, whose health was good enough to be active, and who were interested in coming together as a group. The grandmothers whom we saw only in their homes were larger in number but had fewer contacts with the project because of the greater time involved in reaching them individually. Reasons for their reduced participation in the project included: transiency between the city and home community, lack of interest in participating, poor health, and family caretaking responsibilities. Different efforts to draw them out had varying degrees of success, and some grandmothers became willing to join group activities. For others, the social and cultural leap was too great. Our industrialized urban environment was not a comfortable and natural home for many of the grandmothers. As Park[231] observes, in this setting "the destruction of the communal way of life is more complete, which makes it difficult to recover what might be called 'people's interactive knowledge,' that forms the basis for communal unity."

Despite these constraints, over the span of the health assessment the grandmothers increasingly played the role of co-researchers. With the dissolution of the advisory committee, I regarded them as the primary participants on the research team. By then, many were comfortable with the project, each other, and me. They were becoming accustomed to the notion of doing a health assessment together and were drawn into it more tangibly through the subsequent stages and steps of the research (as described in the rest of this section). First, they played a central role in employing the research associates. Then they were the primary informants in the individual and group interviews. Concurrently, they assisted with data analysis and interpretation at the group interviews. Later, they revised and endorsed the health assessment model and thoroughly reviewed and revised several drafts of the assessment report. Also, the grandmothers and staff functioned as the informal steering committee for me on how the assessment would be conducted, endorsing or correcting moves and directions that I suggested for proceeding.

Research Associates

The final participants to join our research team were the research associates. In early October 1993, just prior to the dissolution of the advisory committee, I attended a conference which featured presentations from people in the North West Territories on PAR.[†††] In their projects, local people were hired and received research training to work with an external researcher. Their approach gave me the idea of employing "research associates" who could (a) devote more time and effort to the health assessment than was available from the advisory committee, staff, or grandmothers, and (b) function as cultural mediators between the advisory committee and grandmothers and me, enhancing the understanding of health assessment, PAR, and the research steps.

In preliminary discussions with the grandmothers and advisory committee, all members supported pursuing the idea. I secured funding from an educational fund for a three-month employment and training program for two people. Employing them was done as participatively as possible. As the advisory committee was dissolved by the time of their hiring, the staff and I involved the grandmothers in:

- confirming whether or not we should pursue this opportunity to engage research associates;
- defining the job descriptions, lines of accountability, and terms of employment;
- the hiring process; and
- being signatories on their contracts.

At the end of November 1993, we hired two Aboriginal, Cree-speaking women as research associates-in-training, one of whom was 30 years old and the other, in her mid-40s.

The research associates and I spent the first three weeks together as basic training and orientation for their work, using the material developed by the advisory committee, other resources on PAR, community development, and research methods, and periodic contributions of staff.

Thereafter, the three of us met daily for both ongoing training and for coordination and supervision of their work. They attended our weekly get-togethers to meet the grandmothers, strategized with the staff and me regarding reaching more grandmothers and involving them in the research, assisted in developing interview guides, did home visiting and individual interviews, and assisted with reviewing the data and turning it back to the grandmothers at group interview and feedback sessions. The hospital provided one more office space and a meeting room for our use.

The research associates gave the health assessment more visibility and substance. Also, through them the grandmothers were drawn closer to the assessment initiative by working with me on establishing their terms of employment and hiring the two individuals. With the research associates, I found a clearer role to play in steering the health assessment. In their early weeks of employment, I recall thinking to myself with much relief and satisfaction, "At last I have a captive audience!" By this I meant that I finally had others who could devote time and attention with me to this health assessment, a focus which was proving to be elusive.

The research associates were able to reach out further into the community than the staff had time for; they contacted and interviewed a greater number of grandmothers, thereby attracting more to the project. Discussions with the associates, especially during their orientation, helped concretize and clarify aspects of the assessment. Their input was valuable for developing the interview guides, analyzing the data, and contributing to discussions with the grandmothers in group regarding data collected. Like the staff and me, the research associates participated in the health assessment in an executive capacity.

Into the second month of their work, however, their performances began declining. Punctuality, attendance, and quality and quantity of work became increasingly problematic. Every day was a tension between appreciating their presence and contribution on the one hand and coping with and responding to their problems and poor work habits on

the other. Far more than I had foreseen, personal issues influenced their employment and participation in the health assessment.

Half-way into the research associates' three-month program, while still seeing their involvement more as an asset than a liability, the staff and I considered running an ongoing research training program based on PAR. We recognized the need for Aboriginal training and employment, the worth of doing research in Aboriginal communities the way we were conducting the grandmothers' health assessment, and the potential of having an ongoing roster of research associates-in-training as a complement to the project's staffing. We put several months of effort into writing proposals and lobbying Aboriginal training programs for support. We secured an approval, in principle, on one proposal but lost out in the program's budget short-fall. To support our efforts, the director of our project allocated funds to keep our two research associates employed past the initial training period, for a total of 4.5 months so that their continued work could contribute to future project evaluation.

To summarize, in the first year of the health assessment, four groups were involved with me: the advisory committee; staff; grandmothers; and research associates. With members of all these groups, I worked to build relationships, develop trust, and engender common interest in participatory research.

Reflections Committee

A fifth group, which I called my reflections committee, was involved in the research in another capacity. Since I was inexperienced in PAR and anticipated needing guidance, I asked nine individuals, including four from my doctoral committee, to meet with me periodically. Initially, the group acted as a sounding board and offered counsel on how to function best in my role of facilitating the participatory health assessment, and later reviewed my findings on the outcomes of the grandmothers' participation in the project and research. It was difficult to get everyone together at the same time so I met with people individually or in groups of two to five, for a total of eight times. The sessions were useful, providing

an opportunity for me to synthesize and summarize what was happening in the project and research in order to update the committee, get feedback on moving the research process forward, and increase the trustworthiness of the research through "peer debriefing."[232] Also, the sessions provided the committee members with a chance to learn about PAR through my experience.

Project Programming

This section describes the various activities of the project as a whole involving the grandmothers, staff, and me, ranging from individual home visits, to group activities, and outward to engagements with community initiatives.

As the staff began the project, they asked the first grandmothers contacted how they would like the project to operate. The grandmothers suggested getting together weekly to meet one another, to have educationals on health concerns, and to hold healing circles.

Formally, my role started with the project in February 1993, following acceptance by both staff and advisory committee. In order to be integrated into the main project programming with the community grandmothers, I offered to contribute to educational sessions on topics of the grandmothers' choice. At the project's first get-together, the grandmothers expressed an interest in learning more about diabetes and nutrition. At the coordinator's invitation, I prepared some relevant information and met them the next week.

These get-togethers, held on Tuesday mornings, became the central group activity. Each Monday, the staff, or later the grandmothers' phoning committee, phoned the grandmothers to confirm who would be attending. The next morning, the staff and I picked up those coming, and got there to start about 10 a.m. Most days, we met in a large room adjacent to the staff office. If the hospital needed that space we would be assigned another room. We always made tea and coffee and had a snack.

76

Through most of the first year (1993), we alternated the Tuesday mornings between healing sessions and educationals. Healing circles are a cleansing and healing practice combining various traditional and contemporary practices: sweet grass; prayers; a blessed stone passed from speaker to speaker; a circle format; one by one speaking and sharing personal experiences; silent, resonating compassion from the listeners; and group support and confidentiality. The education sessions were learning opportunities on various health related topics, usually with a speaker providing information and a discussion period to respond to questions and share experiences.

The healing circles   At the beginning of the project, the grandmothers' decision to alternate weekly healing circles and educationals worked well. Later, when other demands and interests arose, they made up a schedule with healing circles only monthly.   The grandmothers concluded this was a loss, but only acknowledged it after the project closed.   Also, the traditions of sweet grass smudging and a talking stone in the healing circle were stopped because of a grandmother's repeated objections, based on her fundamentalist religious stance and a difference of opinion on how the ceremonies should be conducted.

During the project evaluation and participation interviews held with individual grandmothers in September, 1994 (described in section 4.3), almost all named the healing circle as the aspect of the project they liked best (even though no one suggested restoring its bimonthly frequency). The healing circle format and purpose was one that was both familiar and useful to the grandmothers.   It provided an opportunity for each woman to talk, in turn, about what was most important and immediate in her life, confiding stresses and pains and sometimes joys, and receive love, support, and counsel in return. It was here that the grandmothers' concerns, worries, fears, and pains were validated by others who had similar experiences.   The healing circles were always moving experiences, the emotion and empathy within the group palpable, and the grandmothers drew strength from the compassion and caring of the others.   The use of the sweet grass smudging and talking stone gave a spiritual and ceremonial tone to the circles that was missed when these

77

rituals were discontinued. While the project as a whole provided a rare opportunity for the grandmothers to be cared for, the healing circle was the part of the project where this was best expressed.

The educationals were always on topics suggested by the grandmothers, and usually the invited resource people were well prepared, interesting, and relevant. When community guests joined us either at their request or ours, the quality of the dialogue was variable, depending on the guest's style and the composition of grandmothers at that session. During the educationals or other events, some of the grandmothers actively participated with questions and discussions, while others were shy and silent. These differences were influenced by both the degree of their association with the urban culture up to this time and their basic personality. Initially the topics chosen were on common diseases or troublesome conditions but later, as their trust rose in the project, the grandmothers identified more social and sensitive themes such as stress, wife abuse, child tax benefit, veterans' benefits, and breast self examination.

Periodically, I encouraged the grandmothers to function as their own resource people, to recognize, affirm, and use their own experience and knowledge. At times they agreed, and we held discussions amongst ourselves on topics such as diabetes or stress management. More often, the group wanted a guest to present material to them. The grandmothers enjoyed the novelty of a new person and information, but also had difficulty thinking of themselves as knowledgeable. They did look at the others in the group, especially the ones older than themselves, as fonts of wisdom and knowledge, but not themselves. Each individual was unaccustomed to being recognized for the resources she had. Most had the lifelong experience of being criticized and shamed by the dominant society, residential school life, and dysfunctional family members. As Gaventa[233] found as well: "The people's own knowledge is depreciated, even by . . . themselves, who have internalized the degradation of their own experiences." Since most struggled with low self-esteem, trying to draw out their knowledge was a slow and challenging process.

Over time, the grandmothers developed other interests for their time together, and there were demands for their attention from community groups. With the staff, they set up a revised monthly pattern of a healing circle every third Tuesday, and a birthday party every fourth Tuesday to celebrate all the grandmothers having a birthday that month. The other Tuesdays were filled with a variety of activities: educationals; project planning and organization, including the health assessment; and speakers from committees and initiatives wanting the grandmothers' participation, such as a neighborhood group concerned with children at risk, the new Aboriginal liaison police officer, a diabetic education project, and planners of a poverty forum. Also, during the summers, we had excursions to parks for a picnic, to a local Aboriginal heritage park to plant a ceremonial project tree and visit the displays, and to other sites of interest.

Nonetheless, no matter what the weekly agenda was, our get-togethers were enjoyable. As we got to know one another better, the warmth of the relationships and the amount and spontaneity of humor and laughter increased, and we were genuinely glad to see and spend time with one another each week. Our get-togethers always included food, too. Initially the staff or I brought fruit and crackers, but soon the grandmothers volunteered to provide the lunch, and we usually had a generous spread including bannock, the traditional bread.

Overall, the grandmothers' activities vis-à-vis the project programming included:

- participating in the Tuesday morning get-togethers;
- meeting in their own homes with staff or me for individual support, interviews, or planning special events;
- sitting on community committees, for example the police chief's seniors' advisory committee, the Aboriginal committee of a long-term care facility, and the Aboriginal subcommittee of the local health district board;
- participating in special events such as workshops of an intercultural grandmothers' group in the southern part of the

province, a community development workshop--"*pasantia*"--at a
Metis historic site, public meetings on nuclear testing in the
South Pacific and a uranium waste storage proposal for the
province, and an elders' workshop at an Aboriginal high school;

- participating in in-service or other educational events for the
  staff of the community clinic;
- participating in Aboriginal consultations with city council, the
  city health district, the provincial health council;
- catering soup and bannock on request;
- and organizing special events such as the project's blessing feast
  and Christmas dinner.

The staff's time was devoted to organizing the Tuesday morning group,
doing home visits to support individual grandmothers, attending
meetings of other agencies or sitting on committees with related and
relevant mandates, advocating for individual grandmothers and making
referrals, organizing the grandmothers' involvement in various
activities, staff planning of the project, keeping client files and other
documentation, and assisting with the health assessment.

The project produced three publications--a 1995 calendar with the
grandmothers' photographs, birthdays, and teachings; a book of the
grandmothers' stories of their early life recollections; and the health
assessment report.   The calendar was funded by a federal grant from an
application written by a committee of grandmothers, staff, and me, and its
production was guided by this group.   Different Aboriginal communities
and groups in the province had put out photograph calendars in recent
years and the grandmothers suggested that they make one of their own,
with their pictures and teachings as a permanent record of themselves in
the project for their grandchildren.   The stories' book was an idea from
the staff and an Aboriginal nursing student who was sponsored by an
employment program to work in our project for two summers.   The
student collected and recorded stories from the grandmothers.   Later, the
project director and coordinator worked with a local literacy group to get
a publishing grant, and again a committee with grandmothers guided the

production of the book. The health assessment report was put together collectively, as described later in this section.

The publications pleased the grandmothers. They had not seen themselves in print before, and doing so was flattering. The amount of attention and status they were given because of these books showed their families and the community how well honoured and respected they were. Also, these publications meant leaving a written record of their values, beliefs, and experiences for their grandchildren, the generation on which they showered their love.

This section, then, was an overview of project activities within which the health assessment was conducted. Next is a description of the assessment itself and how it was planned. Further steps follow--consent, data collection and analysis, results and information produced, and action taken.

Developing the Health Assessment Design

To conduct the health assessment using PAR, the original core group of advisory committee, staff, and I needed sufficient time together to become a team, clarify what we wanted to accomplish, design and conduct the research, and critically reflect and act on the issues arising. The director and I, with the agreement of the advisory committee, decided that the assessment could be designed and launched best in a series of workshops specifically devoted to this initiative. These workshops were held in 1993: one day in March, one half day in June, two days in October. The workshops were aimed at building a core research group, deciding on a research design, and following through to do the health assessment. In consultation with the staff, I planned the draft agendas and reviewed these with the participants at the beginning of the workshops. The topics covered in the three workshops are listed in Appendix B. As well, at all workshops, we used exercises for warm-ups, energizing, trust and group building, and relaxing. Following each workshop, I made detailed notes and distributed these to the participants.

The three workshops with the advisory committee and staff to plan the health assessment met with mixed success. The first one was held at a retreat house on the edge of town, and the staff and I invited the committee to "a one day retreat" to plan the health assessment. A draft, ambitious agenda was developed by the staff and me and reviewed with the committee for their input. We got through much of it, with many topics discussed and decisions made; the participation was high and lively.

Several areas of disruption or confusion arose at this first workshop, however. Only four of the five committee members attended; our elder was absent. Towards the end of the morning, one of the members spoke up saying she had thought she was coming to a silent, religious retreat, not a day of work, and she was quite put off by the difference. Part way through that afternoon, in the middle of a discussion I was facilitating on a health assessment topic, another member broke in and asked, brusquely, what I was doing in the project and was I to be staying. These questions occurred even though she had endorsed my participation at the meeting at the end of January, and my role had been restated by the director at the beginning of this workshop. I was taking a prominent role in the workshop as the facilitator moving us through the agenda, and became the focus of her challenge. In response, I reviewed my entry to the project and role within it. The incident showed both a lack of clarity regarding my place in the project and a discomfort on the part of this member about the amount of control I, as a new participant, appeared to have.

A well-respected elder, external to our project and whom I knew well, was invited to the workshop and planned to come for the afternoon but was ill. If she had been present, I believe this challenge to my presence would not have occurred. Her friendship with me would have signaled acceptance by the Aboriginal community at large, and would have assuaged doubts about my role.

The second workshop, a half day in June, continued the development of the health assessment research design, with the same project elder and one other member absent, but with the addition of our new member, a

younger grandmother from our Tuesday morning group. With me facilitating, we filled in the cells of a research design chart based on our discussions from the first workshop and elaborated on at this one. I suggested starting to operationalize this design by doing a "community listening survey" over the summer, and the members agreed. The topic areas for the survey fell into two categories--the community itself and older Native women. As we ended the workshop, I proposed to the advisory committee that I organize the research design into a guide for the "community listening survey." During the summer months, each advisory committee member and staff would listen for information in the Aboriginal community on the various questions of the research design and write down the information, for example, who has influence and how decisions are made in the family and community. I developed the survey tool in hard-covered notebooks, pasting in the list of questions (see Appendix C) we agreed to ask from the research design. I passed the books to each member individually while explaining its use and purpose again, adapting one copy to a sketch pad for a committee member who preferred to express what she heard through art. It was at this June workshop that the division between First Nations and Metis women (described earlier) was raised, and that tension was never resolved satisfactorily.

The response to the use of this community listening survey method by the committee was poor. By the end of the summer, only three of the six (plus one volunteer grandmother) submitted anything on the survey, and only a small part of what was written was on topic. This method had seemed to me a straightforward, appropriate adaptation of the committee's brainstormed ideas on what we needed to know for the assessment, but it had not worked. I heard three explanations: time was not taken over the summer holidays to do it; members' own brief responses were written rather than collecting data from others; the notebook was lost. It appeared there was lack of both clarity and commitment. For the members to conduct this survey, we would have needed more time and discussion to devise an approach that was better understood and valued enough for those interested to use it.

The October workshop was attended by only three of the original five advisory committee members the first day and only two on the second day, plus the grandmother who joined in June, and three new grandmothers who joined at this meeting. Of these latter three, two stayed only the first day; both their absences on the second day were for reasons of poor health. These three new members had background documentation and some briefing from the director on the committee but they were new to the advisory and planning side of the project and the health assessment. With such fragmented participation and variable familiarity with the health assessment, the composition and capacity of this group as a research core group appeared tenuous.

The first day of this October workshop was productive in terms of the health assessment agenda, with much good discussion. The morning of the second day turned into a free-flowing discussion on widely ranging topics of Aboriginal people. I did not attempt to steer the group back to the agenda because I felt this talk was important for accommodating members' interests. In the afternoon of the second day, several points of tension arose: intimations that the financial picture of the project was not clear and accessible to the advisory committee; a reaction and charge that there was too much bureaucracy at the advisory committee level because of a form the staff and I circulated asking for members' commitment to assisting the project with various tasks; a member's personal stress with her family's court case that day; misunderstanding on the part of an original member regarding the addition of the three new grandmothers to the committee; a statement by one member that she was brought up right and would not speak for anyone else (referring to the other grandmothers), and implying that others were not brought up that way. At the end of the volatile afternoon, one member proposed that the project did not need an advisory committee at all and should therefore disband.

The committee had had no meetings since the June workshop, the composition was different, and people were at varying levels of familiarity with the issues. There was little group clarity, cohesion, or trust. Miscommunication was occurring in several areas and on many

levels. These workshops were planned for the health assessment, but since we were able to get people together so infrequently there was much group building as well as other business to be done. The participants brought many personal issues to the table that were not resolvable in that time frame or milieu, but which influenced how the group functioned. The physical health and social situation of some of the members limited their ability to stay long enough to work through group issues and agenda items. The advisory committee, which did not have ownership or control over the project and did not decide itself that the research needed to be done, showed that it was not committed to the initiative.

Another point of confusion was that even though, in principle, the health assessment was to be done participatively, the intent had not been operationalized in the budget, staff duties, or programming plans. When I joined the project, it was necessary to negotiate commitments of resources to support legitimate participation. In order to reallocate funds for the health assessment planning workshops (facilities, meals, honoraria), I agreed to do the project evaluation thus freeing up funds scheduled for an evaluator.

Also, although it seemed logical at the time, in some ways it was a disadvantage for me to be assigned specific responsibility for the health assessment for it was seen thereafter as "my" work. I had to struggle constantly to have it viewed not as my work but as an integral part of the project and as a programming theme, with involvement by all but under my facilitation. In our project planning for the assessment, these two elements--sufficient resources to build a team and conduct research participatively, and explicitly shared responsibility--were both underestimated.

Despite the difficulties, during the three workshops we accomplished some things: the concept of a health assessment was fleshed out and became more of a reality in the project; some assessment issues were examined, such as consent, methods of documentation, assumptions; enough was developed to form the basis of later training for the research

associates regarding an orientation to PAR, and an initial research design which evolved into the interview guides.

With the dissolution of the advisory committee in mid-October, the core research group was reduced to only the staff and me. The project grandmothers were to take over guidance of the project, replacing the advisory committee, but how they would take over as co-researchers of the health assessment was not specified since they did not have a clear understanding of it. By the end of the next month, however, the assessment was made more tangible to the grandmothers because of their involvement in the employment of the two research associates. Hiring them gave me the opportunity I needed to both draw the grandmothers into the health assessment and make it concrete and real to them. By early December, 1993, our research core group was composed of the grandmothers, staff, research associates, and me, and progress accelerated. I had different expectations of the role the grandmothers could play, in contrast to the advisory committee, with their limited capacity. As well, we had the research associates as full-time workers.

The two associates and I, with staff input and continuous consultation with the grandmothers, revised the research design and developed a series of three interview guides to use with the grandmothers (see Appendices D, E, and F) in semi-structured interviews. Each guide focussed on a different area: (a) "past strengths" which asked about the grandmothers early family and community life, stressing happy and strong beliefs and practices (b) "present strengths" which asked similar questions but about life today; and (c) "issues, problems, and concerns" which asked about their greatest worries and difficulties in life now. All three guides included the following sections: an introduction to the interview, the purpose of the health assessment, verbal consent, specific guiding questions and subquestions, critical analysis and probing questions, and closing. The staff reviewed and revised these guides and the grandmothers endorsed them.

Because of the limited capacity of and accessibility to the grandmothers, I abandoned the notion of trying to repeat with them all the developmental

86

work done with the advisory committee on PAR and health assessments. I reasoned that the grandmothers' participation would be achieved more practically and successfully by involving them in research decisions from this point forward, having them advise the research associates' work, being the principal subjects of the assessment, and being active in the data validation, analysis, and interpretation. This altered role was a compromise, based on my judgement that the grandmothers would understand less than the advisory committee had about the assessment design and that, consequently, it was the most pragmatic way to move this initiative forward.

By the end of 1993, the assessment had a preliminary design, the research associates were hired and in training, the grandmothers had taken over from the advisory committee as co-researchers, the assessment was increasingly being viewed and accepted as a concrete part of the project, and we were ready to begin interviews on the grandmothers' "past strengths."

Consent

This section describes a key step in carrying out the health assessment-- establishing terms of consent acceptable to the research team and university research ethics' requirements.

After our first health assessment design workshop, I felt encouraged that our proposed participatory research would be possible. In April 1993, therefore, I submitted a request for approval to conduct the health assessment research to my university's advisory committee on ethics in human experimentation. I wrote and attached to the application form a cover memorandum asking to use a verbal agreement in place of a signed consent. In my application, I put forward two arguments.

First, in conventional research, the standard consent form is designed to protect the privacy of the research subject and to protect the research subject from involuntary participation and harmful results due to the investigation by the researcher. In the case of PAR, the roles of the

87

researcher and researched are changed with the latter being co-researchers. Thus, it is more appropriate to develop an agreement among members of the research team of which the co-researchers/informants are part. This agreement would cover the areas of concern: voluntary participation; protection of individual privacy; and safeguarding subjects from harmful results.

The second reason was that the project staff and advisory committee insisted that to ask them or the other grandmothers for a signature on paper would be considered disrespectful and not in keeping with their traditions. They said a formal signature was culturally inappropriate. The staff and I agreed that until the advisory committee members and the grandmothers had built up a stronger relationship with the project, this issue would be set aside. Further, my suggestion to audiotape the interviews was turned down by the advisory committee, staff, and grandmothers.

The ethics committee approved my application but instructed me to ensure the understanding of voluntary participation on the part of the subjects and to submit further information and measures as used. I was immensely relieved with this approval because if the ethics committee had decided I could proceed only with signed consents, the health assessment would have been stalled.

Routinely in the project, we asked for voluntary participation and permission to document. At the beginning of our Tuesday morning get-togethers, the staff explained that the aim of the project was to support the grandmothers' health, to identify their health needs, and to work to better meet them. The staff expressed the wish to record, anonymously and confidentially, the grandmothers' issues of concern and pertinent comments about health problems and approaches to address these, so as to document the women's needs, to gather information for ongoing program proposals, and to evaluate the project. The participants were asked for their verbal permission. This explanation was conducted in English, and in Cree if there were grandmothers present who were more comfortable in that language, and this procedure was followed throughout the first

year of the project. Thereafter, the request was made if we had a new grandmother join the group. When it seemed appropriate, I took notes during a session, but if not I recorded as soon as possible afterwards. Now, with the ethics committee's approval, for each individual and group interview for the health assessment, the interviewer read the consent terms and sought verbal consent from the grandmother(s) involved.

The next year, in September, 1994, for the project evaluation and participation interviews (described in section 3.2), I reviewed with the grandmothers the rationale for using signed consents and the advantages of audiotaping, and this time they agreed. It appeared that their trust in me and the assessment had increased, and they were comfortable with aspects to which they earlier objected. Now the grandmothers were making decisions about the assessment based not on previous experiences or opinions of research, but on the worth and logic of this specific piece of work, which did include their developing trust in me. Building trust in the assessment and in me, a person external to their cultural group, took time, mutual respect, nurturing, and honesty. Once the grandmothers felt sure that I was trustworthy, they extended that trust to the research I was guiding.

The assessment itself had taken a year to get this far, to the point of formally collecting data, and had unfolded tentatively and ambiguously. All that had been happening, or not happening, was intrinsic to a process that is allowed to evolve and emerge naturally. But not having worked through the process in practice before, it was hard for me to truly trust that this was PAR, that what we were doing was going to amount to anything, and that the specific health assessment was only the tangible task of a larger process of participatory inquiry, reflection, and creation of new knowledge that *was* proceeding.

In November 1994, I sent the university ethics committee copies of all the data collection tools and verbal and signed consent forms we had used in the study, both for the health assessment and my research on participation.

Data Collection

This section describes the data collection process, methods, and sources we used to conduct the health assessment. The data are not the subject of this thesis but are summarized in the health assessment report, Sharing our Health Circle (see Appendix A).

To collect data, we used a variety of methods:

- directly through individual, semi-structured interviews of personal experience and opinions, and group interviews which included giving feedback from individual interviews (hereafter known as the group interview and feedback sessions);
- indirectly through participant observation with unobtrusive recordings, and through formal note-taking with written documentation of project activities and process and for briefs, presentations, and program evaluation;
- recording by audiotape and videotape of selected activities; and
- documenting in my field notes and journal my own impressions, ideas, and feelings as ER.

All the data we collected were qualitative. As a rule, PAR emphasizes qualitative rather than quantitative data, following the dictum: "The heart has its reasons which reason itself does not at all perceive."[234] The choice of research methods is a political decision.[235] By choosing methods that were comfortable, familiar, and personal, and by using the grandmothers as the principal source of data for interviews and participant observation, we were affirming their role as primary participants in the research, their knowledge and experience as valuable, and their empowerment as the chief purpose of the assessment.

The interviews were the most visible method of collecting data, and the basis of all interviews is the question.[236] In our health assessment, the individual interview conducted by the research associates, staff, and me with grandmothers provided an opportunity for a conversation with minimal distraction, while focussing on specific topic areas of a single

grandmother's experiences and opinions. It was also a time to develop relationships further between the interviewer and the grandmother. Kirby and McKenna believe that interviews are "a special form of interaction between people[237] . . . a sharing of ideas and philosophy and experience and symbolic expressions . . . a sharing of self."[238] Oakley[239] distinguishes non-exploitative interviews as those in which the interviewer becomes more than an instrument of data collection by being considered a source of information his/herself. The interviewer interacts with the subjects and records his/her own commentary. Moreover, the individual interview was a time to ask reflective, probing, problem-posing questions to pursue a question further and try to deepen analysis of a response. Freire[240] established the centrality of interview dialogue in raising the consciousness of participants. Early practitioners of PAR, as already cited, similarly emphasized the dialogical interview but of a problem-posing nature which makes PAR unique among research approaches. This type of dialogue provides a forum for:

- interaction between members of the research team--subject and interviewer;
- critical analysis by the participants of their reality; and
- examination and production of collective knowledge.

To conduct the individual interviews, the staff, research associates, and I divided up the total list of grandmothers, with the research associates taking the most names, since interviewing was their principal function. If a grandmother had had little contact with the project to date, the interviewer telephoned and made an appointment for a first "friendly" visit, at which time she requested a return visit to do the interview. If a grandmother had close contact with the project and/or knew the interviewer fairly well, the interviewer would request the interview directly. The interviews were always conducted in the grandmother's home, in the language of her choice, and the responses were hand-recorded. Initially, we planned to complete a set of three interviews with each grandmother--on past strengths, present strengths, and problems--done separately, over a period of three to six months. In fact, we managed to conduct past strength interviews with all the grandmothers we

thought would participate, present strengths interviews with most of them, and problems interviews with only a few, before we ran out of time and the grandmothers' forbearance.

For the individual and group interviews, I emphasized to the staff and research associates that the primary purpose was the grandmothers' empowerment through eliciting their strengths and, at the conclusion of the interview, by summarizing, acknowledging, and validating these strengths. The secondary purpose of the interview was to gather data to contribute to the health assessment. We discussed proper and standard interview technique, and practised the procedure with each other.

In both the past and present strengths' interviews, we got a substantial amount of repetition in the data gathered and could have stopped earlier than we did. Since our primary purpose was to validate the resources of the grandmothers, however, we continued interviewing all those we felt would be responsive to and benefit from the experience. By the time we got to the interviews on problems, issues, and concerns, the employment term of the research associates was over and summer was coming, so we suspended the interviews until the fall. Then, when I proposed to the grandmothers to start again, two of them objected to being asked about their problems so we agreed to complete that part of the assessment as a group (explained later in this section). That group interview was done later on a Tuesday morning and audiotaped.

The individual interviews on past and present strengths were well received by the grandmothers because they enjoyed the time spent with the interviewer recalling happy times in their early lives and reflecting on the joys in current times. In their stories and responses, the grandmothers identified many values, attributes, resources, and accomplishments that were noteworthy. They did not recognize them as such, however, so were surprised and pleased when these were summarized, acknowledged, and honoured by the interviewer at the conclusion of the interview.

The group interview and feedback sessions were held in the Tuesday morning get-togethers. We conducted these interviews by presenting to the grandmothers, one question at a time, responses from the individual interviews on which the staff, research associates, and I had done some preliminary analysis. With these data, we solicited from the grandmothers in the group their verification, correction, clarification, and supplementation, and we hand-recorded their responses. This feedback approach allowed us to combine cross-checking our work through member checks[241] with conducting group interviews for further data. Discussion was limited by time available each morning, as there was usually only an hour free following the usual greetings and announcements and prior to the lunch. Each question of the interview guide (the same as used for the individual interviews) was subject enough for that time. Since there were not enough weeks free to cover only one question per week, we squeezed several into each morning. Notwithstanding, the dialogue was always rich and lively.

To provoke more discussion, I brought copies of paintings by a well-known local Aboriginal artist [242] of typical family scenes from the 1930s and '40s. These images successfully evoked from the grandmothers characteristics of community life in their younger years such as sharing, independence, subsistence, accomplishment, ceremony, role clarity. One painting, a head and neck portrait of a grandmother holding an infant, brought out the most response and a word in Cree almost forgotten by most grandmothers: *kisewatotatowin*, which signifies respect, obedience, love, kindness, humility, listening, and generosity. Thereafter, this word and concept became the unofficial slogan of the project grandmothers. In Freirian terminology, these paintings would be called "codes"--cues representing themes from data used to elicit dialogue on the theme.

The group discussion was the standard format we used in the project's Tuesday morning get-togethers; therefore, the shift to a group interview was subtle and smooth. With good results, it provided an opportunity for:

• verifying data, already collected, through member checks;

- further informing the group participants about the question topic by sharing others' responses;
- exploring and examining a question more fully;
- inducing participation from quiet members in response to contributions from others;
- eliciting further data forgotten in individual interview responses;
- enjoying an informal, social experience, similar to having tea and chatting around the kitchen table.

Fals-Borda observed that in many experiences of PAR worldwide, participants have been found to function better as a group. Popular knowledge, as data for PAR, "comes in packets of cultural data generated by social groups . . . [which] can be immediately processed, confronted, and verified by motivated and fully aware participants."[243]

The grandmothers clearly relished the conversations in group on their strengths, particularly those strengths from times in their past; their self-worth and cultural pride were evident. Feminist researchers have argued against the traditional individual interview in favor of repeated group interviews, suggesting that the "collectivization of women's experiences is not only a means of getting more and more diversified information, but it also helps women to overcome their structural isolation in their families and to understand that their individual sufferings have social causes."[244]

Beyond the planned group interviews, the grandmothers' healing circles became *de facto* group interviews, providing the richest data on their problems and concerns. This was an unanticipated use of the notes I made as a matter of course from the healing circles, assuming that the issues raised here would be the substance of responses in later, more formal interviews. The grandmothers, however, were much more comfortable and candid speaking of difficulties in the supportive, traditional circle than they were in a formal individual or group interview, so I relied to a great extent on that data.

In planning for the formal individual and group interviews, I suggested to the grandmothers that we use audiotaping and videotaping to record. They felt uneasy about both these tools and only agreed to hand-written recording. Yet three months later, when I broached the idea of videotaping our group interview and feedback sessions, they agreed. I took this decision as an important shift and indicator of the comfort and trust they were developing in both the health assessment process and in me. We taped several months of Tuesday morning get-togethers when we were preparing for the first city health district Aboriginal consultations and when we had group interviews on the past and present strengths. To date, we have not used the tapes as a source of data because the discussions filmed were also hand-recorded. Possible future uses include making a visual component to a presentation on the project and research, or compiling snippets as codes to trigger discussion on particular topics with other groups, for example, traditional parenting practices with a class for young parents. Nonetheless, there was worth in the grandmothers simply becoming comfortable with the recording of their conversations and feeling flattered that their get-togethers were of value to someone else.

Among the staff, research associates, and me, we conducted 38 individual interviews and nine Tuesday morning group interviews on the grandmothers' past and present strengths. On problems and concerns, we conducted four individual interviews and concluded with one group interview (explanation follows later in this section), and used the data from all the numerous healing circles.

The participant observation and note-taking methods were used by me continuously throughout the project and health assessment, and were valuable data collection methods. In the assessment, I was both participant and observer, a combination Kirby and McKenna[245] judge to be optimal because it provides a quality of data not likely possible by either total immersion in the work or non-interactive observation. Beyond recording responses in interviews, I took it upon myself to:

- take notes in our Tuesday morning get-togethers, to have a record;
- document the type and content of personal and social issues discussed without naming the speaker;
- put together preparatory notes for our consultations with the health district;
- record information at our staff's in-services that would affect the grandmothers, for example, guidelines for home care services and government benefits; and
- record anything else that could contribute to a formal summative evaluation of the project.

As well, in my _field notes_ I recorded everything I heard or saw that seemed relevant to our health assessment and my research objectives: a chronicle of events with descriptions of the setting, people, and activities; direct quotations or the substance of what people said; and some of my own comments about my interpretations, reactions, and feelings.[246] In my _journal_, I recorded more about my personal impressions and feelings--fears, confusion, frustrations, and joys. I distinguished the two forms of recording between that which I would let others read (field notes) and that which would be a private diary and made public only at my discretion (journal). Other sources of data for the health assessment were staff recordings of "kitchen meetings" of several grandmothers talking together, and staff charting from home visits' and meetings.

The richest sources of data for the health assessment were, primarily, my participant observation recordings of the Tuesday morning discussions, and secondarily, the individual and group interviews. We considered other data sources for both strengths and problems--morbidity and mortality statistics, demographics, results of other relevant studies--but decided against them. To use those sources as an overlay to the very personal stories and experiences of the grandmothers appeared discordant. Almost unspoken, with only passing consideration, the grandmothers, staff, and I ruled out their use. Further data for the health assessment were elicited in other ways. For example, the staff and I encouraged and supported the grandmothers becoming involved in

health-related activities, such as the uranium waste disposal issue, helped them become better informed, and recorded their opinions.

Drawing the grandmothers into the health assessment research through activities, rather than repeating the PAR developmental work done with the advisory committee, worked well. The grandmothers became active participants without enduring protracted, more theoretical discussions. They were not a group given to talking at length about unfamiliar abstract concepts of health assessment participatory research. They had already indicated in various ways that they were reluctant to talk about problems or focus on the negative; had biases against research; took part in the project for the socialization, enjoyment, healing, and learning about specific issues that faced them; wanted to come to the group as it was convenient rather than being held to participating in something like a research team which demanded continuity and time commitment; and were more comfortable doing and talking about things that were familiar to them.

In early September, 1994, I was confirming arrangements with the grandmothers for another set of individual interviews for the project evaluation and the effect of their participation in the health assessment for my thesis research. When I proposed also getting back to the problems interviews for the health assessment, one of the grandmothers expressed annoyance that we would do yet more interviews, saying that we had spent enough time on the assessment. A second grandmother, who was quite new to the project, criticized me for studying the problems of Aboriginal people: "Do you White people have problems? You're good at hiding them. You study our problems all the time. We Native people don't want to be telling you our problems." The first grandmother added, "I can relate to what [she] is saying. We talk and talk and nothing ever happens or changes."

The project coordinator stepped in and responded that things were changing because of the grandmothers' speaking up, and that we had been focusing on the strengths in the assessment, not the problems. The coordinator and I together reviewed the decisions we had made as a

group, the balance being struck between strengths and needs in the health assessment, and my role facilitating the grandmothers to do their own research. I asked all the grandmothers present whether they would prefer to discuss the problems for the health assessment in a Tuesday morning group or continue in individual interviews in their homes. The two who had challenged the process spoke up choosing the group format; the others silently agreed. A group interview would provide peer support for the grandmothers as they spoke to more difficult questions and clearly was seen as less threatening by these two.

Likely, the grandmothers' histories with oppression underlay their reaction to the "problems" interviews. To answer questions on difficult and stressful parts of their lives meant admitting to and revealing painful, possibly shameful aspects of their lives to another person, acknowledging cultural and family breakdown. Their bias against research reappeared, notably in the one grandmother who had not been part of our earlier discussions on the grandmothers controlling and owning the research. Despite the acceptance they had extended to me, I was still a White academic proposing to inquire about their problems. This was reminiscent of the dominant society's stereotypic impression of Aboriginal people as problematic and of the exploitative research that had been done on their people previously.

There are several other possible explanations for their reactions:

- interview fatigue--most of the grandmothers had been interviewed many times for various reasons including but not restricted to the health assessment;
- conflict--periodically, a grandmother would disagree with and be critical of whatever was going on in the group;
- compliance--rather than continue a disagreement, most grandmothers would let the vocal ones be the only voice, and express opinions for the group;
- interview distress--unlike the interviews on strengths which were happy, enjoyable experiences, the interviews on problems

might be disturbing, painful occasions, and thus not something to anticipate with pleasure; and

- project respite--the project offered the grandmothers some relief from the distress in their lives. By focussing on problems, it might no longer be seen as a place of respite for them.

We conducted the group interview on problems and concerns at a Tuesday morning get-together in early October with six grandmothers attending and participating. I introduced the session by reviewing the health assessment to date, describing it as a picture of the grandmothers' health--both strengths and concerns--and pointing out that the latter had been raised already in the healing circles, in health district consultations, the meeting with the Minister of Social Services, and four individual interviews in the home. With the particular composition of grandmothers at the session, I suggested we break up into two groups--Cree-speaking and English-speaking--and respond to the questions from the interview guide that I had written on flip chart paper. Following that small group discussion, which was animated in both groups, we met together and audiotaped the discussion, moving from question to question. These responses were integrated into the section on problems and concerns in the health assessment report. The session went well with apparent ease in raising the issues that were named. Present at this interview was the grandmother who criticized me earlier for studying the problems of Aboriginal people. Yet she participated well in this group format.

Data Analysis

This section describes how we made sense of the data we gathered--the kinds of analysis used; the techniques employed to understand, supplement, and verify the data; and how we organized a meaningful model.

In PAR there are two basic kinds of data analysis: the study of the data for content findings, which in our case was done primarily by me, with the assistance of the staff and research associates; and the critical reflection

on those findings for deeper, political understandings of the participants' reality, which was done by the grandmothers in response to problem-posing questioning and data feedback. The study of the data for content findings includes organizing them, becoming familiar and comfortable with what they have to say,[247] and discovering the "larger, more holistic understanding. The focus is on seeing patterns/arrangements . . . behind the totality of what's being studied."[248] Critical analysis of the content findings involves participants examining their social reality "within which people exist and out of which they are functioning,"[249] "the real, concrete context of facts."[250] Participatory researchers, while acknowledging the worth and place of content analysis, believe that critical analysis contributes most to people "knowing" so that their reality is viewed and acted upon differently.

The staff, research associates, and I informally and continuously analyzed data during our conversations and general discussions from our recollections of both unique comments and recurring themes from the grandmothers. During staff meetings, ongoing training of the research associates, and coffee breaks, we shared our interviewing experiences and discussed both the usual and unique responses we were getting. Even at this level, certain common themes emerged.

More formally, from the written responses of the individual interviews, the staff, research associates, and I did some preliminary analysis of the data according to standard qualitative data analysis procedure--coding, finding themes, and clustering.[251] Coding means identifying "an idea, event, theme or common property that identifies the content"[252] of a piece of data. Similarly coded pieces of data are filed into categories or themes which are elements of theory. In group interview and feedback sessions on selected Tuesday mornings, we took these clustered categories back to the grandmothers to cross-check our work through member checks and for their further contribution of data.

With the grandmothers, both individually and in group, we encouraged critical analysis and interpretation of data, trying to use Freire's problem-posing questioning: What do you hear in this? What does this

mean for you? Is that how it should be? This technique met with limited response. The grandmothers did not readily or easily analyze their lives and/or we were not skillful enough in this facilitation. I do have experience using popular education techniques and tools such as sculpturing and socio-dramas to foster analysis with groups who are my peers. Periodically, I considered the use of such techniques with the grandmothers to provoke more analysis but always concluded that this approach would not be well received by the group because of their age, culture, and personality, nor would it be feasible because of the poor physical health of many of the grandmothers. Because the approach to reflection and discussion that they were most familiar with was sitting in a circle and speaking one by one in sequential fashion, I kept to that format for the most part. I had to trust my intuition on many of these decisions. It is possible that other approaches, such as role plays, might have elicited more critical analysis.

During the summer and fall of 1994, I studied all the data we had collected for the health assessment. Line-by-line content analysis--doing the coding by hand and clustering with Microsoft Word software[253]-- revealed four major categories or themes: traditions, disruptions, concerns, and hopes. Through further study of each of these, subcategories emerged. Park comments on qualitative data analysis: "data are not abstracted into summary statistics, but allowed to speak for themselves as a manifestation of different aspects of the problems. They reveal the connections inherent in the stories that people tell, not through statistical manipulation, but through the events that cohere."[254]

Because the circle is the basic symbol of life and meaning for Aboriginal people, and four is the basic number, I thought of presenting to the grandmothers the categories of data as points on a circle, starting with the traditions in the east, the beginning position on the circle, moving clockwise to disruptions, then concerns, and finishing with their hopes, teachings, and vision for the future. I organized these into a model and displayed them on coloured circles for discussion with the grandmothers and staff.

One of our former advisory committee members was studying and using medicine wheel symbolism in her health management job, so I asked her to join us for the Tuesday morning on which I was to present the draft health assessment data analysis categories. Using visual teaching tools, she described a number of Aboriginal concepts depicted by the circle, such as the circle of life, the four elements, the four seasons, and the life changes' process.

I then followed, explaining the draft categories and proposed model based on the medicine wheel. After some thought and study, the grandmothers agreed in principle, with some changes to the labels, subcategories, and colours.**** One of the grandmothers then declared that this was a good start and that we would work with the model over time and make further changes as warranted.

Over the 1994-95 winter, we studied this draft model on several occasions: at Tuesday morning groups, and at an elders' focus group on health hosted by the city health district's Aboriginal subcommittee. With the grandmothers' endorsement of the model, I drafted the health report and a daughter of one of the grandmothers converted it into a format for easy reading. I took copies to 11 grandmothers individually in their homes then returned to each a few weeks later to record her feedback. After revising the report according to these comments, we reviewed the new draft in a Tuesday morning group. When these changes were incorporated, three grandmothers offered to read the next draft. Of these three, one had no further changes; the other two discussed sections with each other by telephone and one of these two and I spent several hours redoing a few paragraphs which were troublesome. When the report was professionally formatted, ten grandmothers reviewed it individually, then we met a final time as a group in a Tuesday get-together and made last changes. Three of the grandmothers who could not attend that meeting telephoned me with their comments.

Those seven months of ongoing study and revision of the model and report served as a forum for critical analysis of the data for the grandmothers, more so than attempts at problem-posing dialogue did

during the interviews. As the grandmothers reviewed the content of the various drafts, they discussed the meaning and impact of their own and each others' stories, experiences, and opinions. The numerous individual and group sessions we had on the report did cause critical reflection which heightened the individual and collective understanding of the forces and events in their lives.

Information   Produced

The outcomes and achievements of the project and health assessment are many, and are described further in section 4.3 and 4.4 regarding impact on participants and in 4.1 under accomplishments. This next section refers to the report which summarized the findings of the health assessment.

"Sharing Our Health Circle: The Grandmothers' Health Assessment Report" was the tangible outcome of the assessment, capturing and summarizing its findings. This report, assembled by me, edited voluntarily by a university English professor, and reviewed and revised repeatedly by the grandmothers, used the grandmothers' own words as much as possible and photographs of them from their activities in the project. Following the several rounds of review by the grandmothers and incorporation of their changes, final revisions and redesigning were done and 200 copies printed in June 1995.

The grandmothers received their copies of the health report at Tuesday mornings in July or in their homes. From a list drawn up by all of us, the director sent out copies of the report to a wide variety of individuals and institutions, including the community clinic board members and staff, the provincial First Nations association, the provincial Metis association, the city health district, the city tribal council, the Aboriginal high school, a family social services organization, the city planning department, provincial ministers of health, social services, education, justice, and our host hospital.

The report was an attractive 16-page booklet that was well received by the grandmothers and others. As one of the grandmothers said, "This is something very good, and we're proud of it." The report was readable for the grandmothers, its primary audience, and for others to whom it was disseminated. It was a forum for the expression of experiences, thoughts, and opinions of and for the grandmothers but particularly, as some often said, for their grandchildren. As Kirby and McKenna affirm, "Written reports serve as a public record of the research, documenting lives and experience that too often go unrecorded. ... [and] can become a resource for other people on the margins who share similar experiences or questions."[255]

Some of the comments I received on the report included these comments from the Dean of Nursing: "I have just finished reading the Sharing document, and I can't tell you how much it touched me. The grandmothers' voices express so much more than would be included in a formal report-style document." A professor and PAR expert at another university wrote, "Sharing Our Health Circle is a real treasure and I'll introduce it to [the] class I am teaching on the history of adult education in which I rely a lot on oral history traditions."

The project director made a presentation at a health promotion conference and the demand for copies of the report exceeded our supply. A second printing of 1000 copies was done in June 1996.

Action Taken

In response to issues and concerns that arose during our health assessment and other project activities, the grandmothers, staff, and I took action. This was done at both an individual and group level, throughout the life of the project. These are discussed here briefly and further in section 4.3.

Because the staff and I worked so closely with the grandmothers over an extended period of time, and because the needs assessment was interwoven with other programming, taking action on issues that arose

was the natural, moral, and imperative thing to do. In relation to PAR, Park writes that "action takes place concurrently with research activities, illustrating how knowledge and practice are not easily separated and also how the former issues from the latter."[256]

A specific example of this occurred in relation to the grandmothers' identified concern for their physical health, safety, and isolation. One of the grandmothers, in her seventies and living on her own, had a mild stroke in bed one evening and lay there for the next 48 hours unable to move until a neighbor called on her and assisted her up and to a medical assessment. In response, this grandmother and I traced down an emergency alarm system and a local service club that covered the costs for a few seniors who could not afford it on their own. We put in an application and got one installed on the telephone by her bedside with an alarm button she could carry with her. She shared her problem-solving experience with the other grandmothers. As Kirby and McKenna remind us, "The particular needs of all participants involved . . . must be attended to."[257]

Other personal issues were more systemic and resistant to resolution, but these were common, societal issues, such as troubled youth, effects of addiction and poverty, and environmental threats. The grandmothers expressed their concern and some became active with other groups via our project on a specific issue, such as a children at risk committee, a poverty coalition, and an inter-church group formed to resist uranium mining and waste storage.

The lives of these grandmothers were laden with hurdles related to colonialism, racism, poverty, and sexism, and they were not accustomed to feeling empowered enough to confront them. Still, many of the grandmothers were successful in tackling problems at an immediate, personal level so that they and their families had a measure of health. The extent of this success, however, was limited by systemic and institutional barriers.

105

Project Closing

In July 1995, within a month of the health report being published and distributed, I learned I was ill and reduced my time with the project. The staff wound down programming over the summer to take their vacation time before funding expired at the end of September. Since then, the grandmothers, staff, and I have continued to meet informally and keep in touch with each other, up to the time of this writing. In March 1996, funds were found to rehire the coordinator for one year for a new Aboriginal seniors project to reach the more socially isolated men and women, and to encourage the grandmothers of the first project to continue building their community and supporting one another. However, little staff time was available to foster this activity.

During the life of the project and research, the staff and I played a facilitating role in building the community of grandmothers through programming within the group, making connections between them with other groups and initiatives, and providing practical support, notably transportation. When these functions were no longer provided, the grandmothers depended on their own infrastructure built up over the project time period and maintained connection with each other, but it was reduced. Without assistance, most of them were restricted by their physical, social, and economic limitations, and reverted to their most immediate and convenient support and social circles. In Maguire's participatory research with battered women in Mexico, she found also that, while "a 'community' of women did emerge, no enduring organization did."[258] In our work as well, the grandmothers continued to feel like grandmothers of the project and would telephone one another around a special need or event, and a few of them would get together from time to time.

In June 1996, over eight months after project closure, one of the grandmothers telephoned the others and organized a meeting at the local Aboriginal community centre. Eleven grandmothers, the former outreach worker, and I attended. The convening grandmother had received requests from a local Aboriginal heritage site and an Aboriginal

day care for grandmothers' participation in their respective programming, and she wanted to pass these invitations on to the others. As well, a grant the grandmothers had received just at project closing demanded use or forfeiting, so plans had to be made. Also, from calendar and book sales, the grandmothers had a generous bank account which needed a new name and signatories. The meeting was a festive reunion; some of the grandmothers had not seen one another for months. We dealt with business and planned a supper for the next week which was well attended and enjoyable. The community spirit and friendship built up during the project was enough to draw everyone together again. The warmth and love was palpable within the group, and nurtured each of us.

A few months later, in September, the Aboriginal subcommittee of the health district board, with four of our grandmothers as active members, sponsored the first city-wide Aboriginal health fair in conjunction with an all-day program to celebrate International Indigenous Day, sponsored by the local municipal government.

The next month, a group of the grandmothers organized a workshop, "Sharing Our Values," using the grant that had been received prior to project closing. On their own, they put on the program, inviting other grandmothers, an elder, Aboriginal youth and university students, and others interested in the theme. About 50 people attended the all-day workshop at the Aboriginal community centre. Two of the grandmothers were plenary speakers addressing the role of mothers and grandmothers in today's families, and the personal journey of women recovering from trauma; the daughter of one of the organizers spoke on abuse. Later, our grandmothers functioned as resource people for small group discussions on the topics of caring, addictions, traditions and culture, and parenting and elders. The day closed with a large healing circle and a family supper. The health assessment report was the principal document in the registrants' packets.

This description concludes the section on the methodology and experience of using PAR to conduct the health assessment with the grandmothers. The next section describes the methodology of my research on the effects on

107

participants of engaging in the health promotion project and participatory health assessment.

3.2 Methodology to Examine Effects of Participation on Participants

The primary objective of my research was to study the effects on the grandmothers of participating in a health promotion project, one aspect of which was a participatory health assessment. To address this objective, I used a case study approach, examining in depth this PAR-based health assessment. Qualitative data methods were chosen because of the resonance of their characteristics with this study: naturalistic inquiry; context and subject specificity; thick description; and interpretation shaped by the perspectives and voices of the people studied. The data used in the analysis were collected during the 2.5 years of my involvement with the grandmothers' project.

3.2.1 Case Study

Research is systematic inquiry. Descriptive research is undertaken when understanding, "description, and explanation (rather than prediction based on cause and effect) are sought, when it is not possible or feasible to manipulate the potential causes of behavior, and when variables are not easily identified or are too embedded in the phenomenon to be extracted for study."[259] The case study is a type of descriptive, non-experimental research which describes contemporary events, and adds two sources of evidence not found in historical research--direct observation and systematic interviewing[260]. Stake established the central question about case studies: "What can be learned from a single case?"[261] Accordingly, in general, the study is designed to optimize understanding of that case rather than to achieve generalizability.

Yet there is a type of inquiry called "concatenated research" which claims a kind of generalizability. Concatenated research is that in which each study of a particular phenomenon is seen as a link in a chain of studies on related processes leading to cumulative grounded theory. One

108

advantage of this type of research is "that it serves to refute the charge that qualitative research consists chiefly of ungeneralizable case studies."[262]   Notwithstanding, Stake maintains that although a case study may be a small step toward "grand generalization,"[263] that purpose should not be emphasized.

In this research, while the phenomenon of PAR is ultimately of more interest than the individual case, PAR will be better understood through learning from the process and findings of this case. This makes it an "instrumental case study"[264]--a particular case is examined to provide insight into something else. Our research was unique in its setting and subjects and does not lend itself to being replicated or generalized. Yet by providing a thick description of the case, outcomes and lessons which emerged may inform further related inquiry.

Kemmis explains how the use of a case study can be both enlightening and activating.

> If a case study sometimes provides illumination, it does so because in social life and social science we work pretty much in the dark. That is not to say that we have made no progress, nor is it to cherish the mystery of social life as impregnable to human understanding. It is to assert that our scientific understandings of social life have all too frequently fragmented it into "manageable" bits which conceal from us the context-embeddedness of social phenomena, their dynamical coherence, their reflexive effects and their true significance which is in action rather than theoretical discourse. Case study, because it is naturalistic, is especially well-placed to make an assault on that fragmentation and its associated obstacles to our understanding. Case study research is both political and strategic in the sense that authentic insights reached through case study have the capacity to work reflexively to change the particular situation studied.   The action-possibilities created by case study are grounded in the situation itself, not imposed from outside it. Case study is thus emancipatory.   This, then, is the justification for case study work in general: that it is naturalistic and emancipatory.[265]

Notwithstanding the benefits of case studies, there are potential disadvantages which Lincoln and Guba[266] identify: case studies are prone to exaggeration or oversimplification of a situation, and the interpretations depend heavily upon the writer for the relative emphasis on or selection of material to be presented. These points are

acknowledged yet allayed by steps to ensure trustworthiness, as described later in this section and in 4.4.

This case study was designed to gain an in-depth understanding of PAR and its relationship to health promotion. What follows is the methodology used to assess the effects on participants of engaging in the health promotion project and PAR (the PAR methodology and experience were found in section 3.1).

3.2.2 Data Collection

Data were systematically collected over the 2.5 years of my involvement with the project. Some methods used were the same as for the health assessment but with a different purpose. The methods for this research objective were: individual interviews; participant observation; and note-taking. The ability to use multiple methods of data collection is a major strength of case study research which exceeds that used in other strategies, such as experiments, surveys, or histories.[267]

Interviews: Interviews (hereafter known as the project evaluation and participation interviews) were conducted with 14 participant grandmothers in September 1994. The dual purpose was to assess the impact of their participation in the project and research and to evaluate the project. By then, most of the grandmothers interviewed had spent 1.5 years with the project, and slightly less than one year with the participatory health assessment.

The semi-structured interview guide (see Appendix G) was developed in consultation with two members of my doctoral advisory committee, wherein we concluded that the interview questions would encompass the project activities in general. We determined it would be unrealistic to try isolating the research activities from other project programming because the various aspects of the project were so intermingled. This inclusive approach also allowed the interviews to be useful for the project evaluation as well, and made the exercise more concrete for the grandmothers--they understood the need to evaluate the project but less

110

so the need to assess effects on them accruing from participation in the project and health assessment.

On several Tuesday mornings, in the summer of 1994, I proposed and explained the interviews, consents, and audiotaping to the grandmothers. Then the interview guide was reviewed by the staff and grandmothers for appropriateness and clarity. Days prior to the scheduled interviews, each grandmother received the guide for her consideration and preparation. The first eight questions pertained to the grandmothers' responses to participation in the project and the last two to program evaluation.

As explained in section 3.1, by the time these interviews were conducted, the grandmothers had developed enough trust in the project and me that they readily agreed to using a written consent form, and one was signed by all the grandmothers. English was the language of communication for 12 of the interviews, Cree for the other two interviews with one of the grandmothers translating. Twelve of the grandmothers agreed to audio-taping; the other two declined and were hand-recorded by me. The taped interviews were transcribed by a typist and checked by me. All interviews were held in the homes of the grandmothers, and lasted approximately 30 to 60 minutes each. The data from some of the interviews were relatively rich and from others, brief. Following analysis, the responses were returned to the grandmothers as a group in a Tuesday morning get-together for their verification and information.

Interviews were also conducted, one year after project closure, with two of the three staff members who were still employed by the sponsoring community clinic--the director and coordinator. I conducted individual, audio-taped interviews with them using a semi-structured interview guide (see Appendix H) developed by the three of us together as an adaptation from the guide used with the grandmothers; signed consent was obtained. The interviews were intended to serve several functions: contribute to program evaluation; examine effects of the project and research on the grandmothers from the staff perspective and on themselves; and provide an opportunity for staff to critically reflect upon their experience and learning in the project and research.

Participant observation: Observation yields direct data on behaviour seen firsthand, furnishes data on topics that participants are not willing or able to discuss, and gives a further perspective. Merriam[268] identifies elements to be focussed on in observation: setting; participants; activities and interactions; frequency and duration of events; and subtle factors such as what does not happen, especially if it ought to have happened. Data in this research were collected methodically in two records over my time with the project: regular, detailed field notes of the project and research happenings; and a less frequent, but more personal journal documenting my own experience and response to the happenings. The data from participant observation became increasingly rich through getting to know the grandmothers better as individuals, as a group, and in encounters with them in community initiatives. The dual role of researcher and participant affected both the type of data collected and my interpretation of them, and will be discussed in section 4.2.

Note-taking: Beyond the recording an external researcher (ER) would do in participant observation and interviews, I recorded notes as the volunteer scribe for the project and for program evaluation. The content and process of each Tuesday morning get-together were recorded, and I also took notes on planning sessions and participation in special events by the grandmothers such as health consultations. These notes proved to be a rich source of data for the health assessment and the description of the PAR experience, and a secondary one for this research objective on effects of participation.

3.2.3 Data Analysis

The foremost source of written data was the set of project evaluation and participation interviews with the grandmothers. These data were analyzed in the same manner as those for the participatory health assessment--according to standard qualitative data analysis procedure: coding, finding themes, and clustering.[269] The interpretation and elaboration of that analysis was influenced by my observation of the

112

grandmothers over the life of the project and my role as a participant within the project and research.

Following the interviews, I studied the data line by line. Responses to the questions were analyzed in two ways:

- first, by reading through the responses of all the interviews, then from the beginning, coding words, phrases, and sentences according to conceptual themes, then clustering these into categories, using Microsoft Word;[270] and
- second, by compiling all responses to a single question, and reviewing those for "recurring regularities in data."[271]

The two ways were merged to create a single set of categories which represented the themes of the grandmothers' opinions. Line-by-line content analysis revealed three major categories of themes (personal empowerment, group empowerment, external or partnership empowerment) with numerous subcategories. Following feedback from my reflections committee and other persons consulted, and my own further study of the data, I reclustered the data into five outcome areas--cleansing and healing, connecting with self, acquiring knowledge and skills, connecting within the group, and external exposure and engagement-- again with numerous subcategories. The principal determinant of, or influence on, the development of these outcomes in the grandmothers appeared to be *participation*. A theme throughout, in response to increasing awareness of issues and confidence in addressing them, was *action*. Also, the project and community environment which fostered development was characterized by *opportunity, encouragement, mediation,* The interpretation and elaboration of that analysis was influenced by both my observation of the grandmothers over the life of the project and my role as a participant within the project and research.

The audio-tapes from the staff interviews were transcribed by a typist, and the transcripts were analyzed by me, again according to standard qualitative data analysis procedure--coding, finding themes, and clustering.[272] The data provided evidence on what the staff knew about

113

health promotion and PAR prior to and after the project and research, the roles they played, the effects of their involvement on themselves and the effects on the grandmothers from their perspective, and the accomplishments and difficulties of the work overall.

3.2.4   Trustworthiness

This inquiry was an interpretive case study, using qualitative methods and data.   For studies such as this to have an effect on either the theory or practice of health promotion, the research must be trusted and believed; therefore, both rigour and relevance are essential.   Studies need to employ methodology that is sound and present insights and conclusions that are true.

Various authors have proposed criteria to judge the validity or trustworthiness of qualitative studies.   For example, Guba and Lincoln[273] adapted criteria from positivist social science research to suit the post-positivist paradigm.   Accordingly,

- internal validity, judging truth value, becomes credibility;
- external validity, judging applicability, becomes transferability;
- reliability, judging consistency, becomes dependability;
- neutrality, judging objectivity, becomes confirmability.

Others reject the appropriateness of positivist criteria by whatever name for judging post-positivist research.   Lather[274] proposes a reconceptualization of validity for research "openly committed to a new social order."   Those criteria will be used in this study because the overall intent of the project was personal and social transformation, even though assessing the effects of the grandmothers' involvement was a more conventional research piece.   Lather's criteria are:

1)   triangulation which is expanded beyond the psychometric definition of multiple measures to include multiple data sources, methods, and theoretical schemes.   Our research drew on a number of different subjects observed and interviewed over an extended study period

114

(grandmothers, staff, and other community members), and on the perceptions and analysis of myself, the external researcher, and of my reflections committee; multiple data collection methods (interviews, participant observation, and note-taking) and member checks; and theoretical constructs of PAR and health promotion. A thick description of the study is written to ensure a complete presentation.

2) construct validity which refers to the extent that theoretical constructs are operationalized in the research. Participation and empowerment are central elements of the theory of health promotion and PAR, and were core, working principles of the project and the participatory health assessment, and their greater understanding was the motivation behind this primary objective on participation.

3) face validity which is simply looking at the findings and deciding whether or not, on the face of it, they make sense. The findings of this research do appear reasonable and logical.

4) catalytic validity which refers to the degree to which the research raises the consciousness of the subjects about their reality in order to transform it. This research, unlike the PAR health assessment, did not attempt a critical analysis of findings or context.

Also, Merriam[275] argues that the researcher's unique role in qualitative research enhances trustworthiness through both her/his own analysis and interpretation and the nature of the interaction between researcher and subjects. As the primary instrument for data collection and analysis, the researcher has certain characteristics that differ from other instruments. As I was, the researcher is responsive to the context, adapts techniques to the circumstances, considers the total context, expands what is known about the situation through sensitivity to nonverbal aspects, processes data immediately, clarifies and summarizes as the study evolves, and explores unusual responses.[276]

Despite the position that qualitative case studies are not generalizable, the literature does offer caveats. "Concatenated research," introduced earlier,

is the term used for related studies on a particular social subject which are treated as links in a chain leading to cumulative grounded theory.[277] Similarly, related research may be viewed as small steps toward grand generalizability.[278] An instrumental case study focuses on insight into an issue, in this case PAR, which may provide lessons for subsequent research on the same or related issues.

This concludes the chapter on research methodology, both a detailed description of the extensive methodology and experience of using PAR to conduct the grandmothers' health assessment, and a briefer explanation on how my more delimited research on participation was conducted. The next chapter starts with reflection and critique on the PAR experience and the role of the ER, followed by the findings and discussion of the effects on participants of their engagement in the project and research.

˙<u>Endnotes</u>:

* The terms needs assessment, health needs assessment, and health assessment were all used in the project to describe the same initiative. The standard term for this research is needs assessment. Ours was done as part of a health project, thus we sometimes used the term health needs assessment. Part way through our initiative, the grandmothers indicated their preference for emphasizing strengths rather than needs, so we adopted the term health assessment to reflect this change. For consistency and to reflect this shift, I use the term health assessment throughout.

† First Nations refer to the tribes of indigenous people. Metis refers to the descendants of the early intermarriages between indigenous people and French explorers and traders.

⁂ The term Aboriginal is used to describe indigenous people in general, both First Nations and Metis.

†† In September, 1994, I conducted the project evaluation and participation interviews with 14 grandmothers individually, bringing the loosely analyzed results back to them in November for their verification.

*** It could be argued that this was an unworkable premise. In a local newspaper article on August 2, 1996, Aboriginal journalist Doug Cuthand makes the point that with more than 600 individual First Nations in Canada and 50 languages, the Aboriginal community in Canada is as diverse as Europe or Africa. Cuthand reminds us of the misguided assumption many non-Aboriginal people hold--that "First Nations people

are seen as one monolithic group that somehow marches in lockstep" (p. 5). In my personal experience, I have noted, with surprise, many times, the local focus and interest of a specific community and the absence of a larger Aboriginal identity. Cuthand concedes that, despite the variations, First Nations people share a similar religion and respect for the wisdom of elders. The grandmothers' project and our health assessment were attempting to include not only different First Nations (although most were Cree), but Metis who have a unique culture of their own.

††† At the 1993 Association of Colleges and Universities for Northern Studies (ACUNS) conference in Fort Smith, anthropologist Joan Ryan and her Dog Rib colleagues presented their recent work in four projects using PAR.

**** Colours are assigned specific positions on the medicine wheel, so using the Cree colours the categories became (i) traditions - yellow (ii) disruptions - blue (iii) concerns - green, and (iv) hopes - red.

4. Findings and Discussion

4.1 Discussion and Critical Reflections on Doing PAR

In this subchapter, I study the participatory health assessment experience in relation to other descriptions of PAR in the literature (introduced in section 2.2) in order to examine the extent to which our research demonstrated characteristics identified by other authors. First, our health assessment is compared to a set of qualities, stages, levels of knowledge attained by participants, a few general challenges, and a number of results. Next, I present a summary of numerous points of tension and lessons that emerged from the project and our participatory health assessment. Finally, some accomplishments are identified.

4.1.1 The Nature of PAR

Qualities of PAR

As identified in Chapter 2, PAR has many unique features including these five distinguishing qualities: participation in the research by the people being studied; inclusion of popular knowledge, personal experiences, and other common sense ways of knowing; a focus on empowerment and power relations; consciousness-raising and education of the participants; and political or collective action.[279] To varying degrees, our work embodied all of these qualities.

Participation

Participation may be viewed on a continuum from pragmatic to liberating, and from minimum to maximum. On the first scale, our research was explicitly liberatory. The purpose of the grandmothers' participation was their empowerment; it was the means to that end. At

the beginning of the project when the goals were rewritten, it was specified that the needs assessment was to be done using PAR. When I introduced myself and PAR to the staff and advisory committee, it was in terms of research by the subject participants under their own control and for their own empowerment. This research approach was agreed to by consensus reached through ongoing discussions among staff, advisory committee, grandmothers, and me. Amongst ourselves, we first discussed the value of a participatory process in which initially the advisory committee and later the grandmothers would take part in a methodical, guided experience of reflection and analysis about their lives in relation to health and then expressed the shared belief that this could be illuminating, liberating, and empowering for us all. We also proposed that through this process and other complementary programming of the project, the grandmothers could build a community in our city that would serve as a support for them, take action on issues they face, and reinstate their traditional role of respected elderly.

We did not dismiss, however, the pragmatic end of the spectrum. We acknowledged that the idea of doing a health assessment had come from the writers of the project proposal, not from the grandmothers themselves; therefore, a primary purpose of doing the assessment was to honour the terms of the funding. Also, we recognized that the grandmothers would resist being studied by others and that an assessment process and report of which the grandmothers did not feel ownership would be of little use to anyone, particularly them. Furthermore, we viewed the grandmothers as the experts and believed that the most valid assessment of their health would come directly from them. As Freire observed, "The silenced are not just incidental to the curiosity of the researcher but are the masters of inquiry into the underlying causes of the events in their world."[280]

On the other scale of participation, that of minimum to maximum degree, our intent was that the advisory committee members and grandmothers would have maximum participation in the research and in many other aspects of the project. The achievement of this was tempered both by their limited capacity to participate and by the formal authority of the

sponsoring agency. Likely, the advisory committee dissolved largely due to members' lack of interest in their delimited advisory role.

The grandmothers' ability to follow through and participate in any event was restricted. This was due to a number of factors: their own poor health; demands at home; their life experience of isolation and non-involvement; the limited time available on Tuesday mornings; their irregular attendance; and the intangible, unfamiliar concepts of some of the initiatives. Comstock and Fox remind us that "the participatory researcher must always be conscious of competing interests and activities that constrain the degree and types of participation that can be expected."[281] In the health assessment, when the grandmothers could not participate actively, I kept them briefed on progress so that they were consulted and informed at all times.

The grandmothers' active involvement in the health assessment and other parts of the project was valued by them. One of them commented that the participation of the grandmothers was the best part of our health assessment together, and was the respected way of doing things.

Popular Knowledge

PAR values popular knowledge and science, personal experience and feelings, and artistic and spiritual expressions as useful ways of knowing. Both implicitly and explicitly, the advisory committee, staff, grandmothers, and I valued the knowledge and experience of older Aboriginal women in general, even though individual women did not always see this in themselves. Recognizing, validating, and honouring this knowledge was a constant theme emphasized in doing our research. In the initial research phase, I guided the advisory committee in drawing up a research design for the health assessment based on what the members felt would be the most important indicators for describing the health of the grandmothers. Most of the data sources and collection methods that we identified in the design involved listening to and asking the grandmothers about their recollections, opinions, experiences, traditions, beliefs, and teachings. Later, in the interviews with the

120

grandmothers, in keeping with our goal of empowerment, I continually emphasized to the staff the drawing out, naming, and valuing the grandmothers' own experiences, knowledge, and strengths as the basis for the health assessment.

As well, to do research with the grandmothers as active team members, the staff and I found we had to choose approaches and styles which were comfortable and familiar to them. This meant one-on-one and group conversations to decide what a health assessment should look like, to hear their perceptions of their own health and that of their families and communities, and to learn how they would propose restoring, improving, and promoting better health at all these levels. The tangible product from this process, the health report, reflects the continued emphasis on the knowledge and wisdom of the grandmothers themselves.

Empowerment and Power

PAR focuses on empowerment and power and, as in participation, there is a wide spectrum of positions that participatory researchers take on empowerment and on ways to accomplish it. The singular, explicit, intended purpose of both our research and the project as a whole, from the perspective of the advisory committee, staff, and me was the empowerment of the grandmothers, and the primary means to that end was their participation in as much of the health assessment as possible. As well, in the early part of the assessment, my interviews with the advisory committee members were on empowerment in various aspects of their own lives.

To the grandmothers, the concepts and language of power, control, and empowerment were not familiar, even though lack of power and control was the experience of every one of them. They did appreciate the disempowering history of Aboriginal people and the disempowering reality of living in poverty and being subjugated by racism. They recognized that women had lost their traditional, more valued, and powerful position in Aboriginal society. The traits and activities of the

grandmothers which limited their participation in the research are characteristic of a disempowered life.

Consciousness-Raising

Consciousness-raising throws a different light on individuals' own situations and problems by viewing them in relation to larger societal forces. For the grandmothers, this awareness was slow to develop. For example, they could acknowledge readily that, in general, Aboriginal people were subject to racism, but they did not see so easily that their individual, personal problems were caused by power inequities that were related to their race, culture, gender, or class. This issue is further discussed later in this section under "Nature of Dialogue."

Political or Collective Action

Engaging in political or collective action involves challenging beliefs, attitudes, structures, and systems which perpetuate inequalities and injustices. The grandmothers engaged in political activity on several issues: health care policy; civic services; an addictions treatment centre; uranium mining and proposed waste storage; and social services policy (more discussion follows in section 4.3).

Although the staff and I were interested in engaging the grandmothers in political action, aspects of our project's organization and scheduling did not foster concerted involvement. We did not choose issues deliberately to concentrate on but, rather, issues were explored as they happened to come to our attention. Also, we set up a calendar of activities for the Tuesday mornings two to three months in advance, which may not have included any political issues or allowed time for discussion or follow-up to those issues which were introduced at special events. As well, our composition of grandmothers was so irregular that the ones who attended an event might not be the ones at the next Tuesday morning group even if time was made for follow-up analysis.

In summary, our experience demonstrated adherence to the qualities of PAR to varying degrees. The explicit guiding principles of the project and research were participation and empowerment, the grandmothers were involved and acknowledged at every opportunity, and they showed clear evidence of increasing empowerment over time (as described in section 4.3). Their wisdom, experience, and strengths formed both the base of current knowledge and the guidelines for development of new knowledge. Despite the grandmothers' limited interest in theoretical critical analysis or forays into arenas they viewed as "Indian politics," they established their presence and voice in numerous public fora, demonstrating courage and conviction on issues important to them.

Stages of PAR

Another way of looking at PAR is to categorize it into broad stages. As described in section 3.1, our process unfolded into identifiable stages that were intertwined and overlapping, rather than only linear. Reordering the stages of Cancian and Armstead,[282] we emphasized dialogue and negotiation at the beginning, continued orientation throughout, conducted joint research with different participants and intermingled with other project programming, and took joint action as issues, interests, and needs arose.

Dialogue and Negotiation was a prominent yet difficult aspect of this research for three reasons: the stigma held about research by many of the women involved in the project; the fact that the research was identified as an important and useful part of the project not by the women themselves but by the sponsoring agency and funders; and the change in research team members part-way through the project so that the research had to be renegotiated.

Orientation was also a prominent part of this research, not difficult, but essential and protracted. Many differences had to be bridged before I could establish relationships of comfort and trust with the advisory committee, grandmothers, and staff, including: White/Aboriginal; upper middle class/ lower to middle; academic/less formal education;

123

researcher/researched-perception; healthy, slender, physically
active/poorer health, obese, physically limited; English language
speaker/Aboriginal language speaker; privileged life
experiences/disadvantaged and/or difficult life experiences; of the
colonizers/colonized. To a large extent, we adjusted to and overcame these
differences by sharing a variety of experiences, developing trust, and
becoming friends and supports to one another.

Threads of dialogue, negotiation, and orientation continued throughout
the project and our research, as participants changed and new issues
emerged.

Collective research was only one component of the health promotion
project. One achievement of the research was that it integrated well into
the whole project and was consistent and compatible with other
components. It was not seen as an external, separate initiative, but rather
as another part of the project. Moreover, the emphasis of the health
assessment on the grandmothers' participation and empowerment
influenced other activities of the project to stress these principles.

Collective action was taken throughout the project as issues and needs
arose, some at a personal, individual level and others at a larger societal
level, identified through the research process itself and/or other project
activities. We made action a deliberate part of our research and the
project as a whole. During our interviews, other home visits, group
discussions, and consultations around specific topics, numerous examples
arose of issues that affected the lives of individual grandmothers but
often were experienced by the others, too. Frequently, the staff and I
assisted a grandmother in problem-solving a specific incident. If
appropriate, we involved other grandmothers, and/or encouraged the
grandmother to relate her problem and way of dealing with it to the other
grandmothers. Sometimes, we discussed an issue of common concern at
our get-togethers, and several times brought in resource people to give us
added information and assist in our response. Other times, when our
project was invited to participate in an event, for example a city health
poverty forum, we designated specific planning sessions to air our ideas

124

on the questions posed for discussion, and then took follow-up action as appropriate.

These four stages--dialogue and negotiation, orientation, collective research, and collective action--are central to PAR. They do not, however, unfold in a discrete linear fashion as listed here; rather, aspects of the stages occur in a staggered and cyclical way according to the unique circumstances of the inquiry and the participants. They may well be better described as threads or themes throughout a PAR initiative rather than stages.

Levels of Knowledge

PAR may be examined according to participants' level of knowledge:[283] superficial, consequences, causes, and transcendenc, as introduced in section; 2.2.2. When we first started discussing health issues with the grandmothers, they were at a <u>superficial</u> level. They recognized the familiar aspects of their situation--low income, limited physical health, family stress, and isolation. In our discussions and healing circles, we affirmed their reality and encouraged reflection on the <u>consequences</u> of their situation--obesity, diabetes, poor housing, emotional and financial abuse, poor diet, addictions. Through building a sense of group and community, establishing trust, identifying communalities, and continuing to focus on the health assessment, the grandmothers were able to identify some <u>causes</u> of their problems and life patterns: racism, loss of traditional role, poverty, addictions, assimilation, and ineffective health and social services. These instances of insight, while only tentatively articulated at times, show optimism about the possibility for real change, according to Smith and Ornelas. The grandmothers had hope for improvements in their lives in the areas of social and health services and in the reclaiming of some of their traditional role and status through their increased profile and acknowledgement in the project. Yet this ability to shift from an individual focus of consequences to a social consideration of causes showed remarkable movement. This was a <u>transcendence</u> in which they altered their "state of being and their state of affairs" (p. 236). A degree of this movement is evident from the

grandmothers' responses in the interviews regarding the effects of their participation in PAR (see section 4.3). From this level of knowledge, participants pass "through to a new, and again superficial, level of knowledge" (p. 236). Growing awareness and knowledge form an ascending spiral of conscientization.

General Challenges

As introduced in Chapter 2, three specific challenges of the paradigm and methodology of PAR emerged from my review of the literature. The first, regarding PAR's androcentricity, affects the overall paradigm rather than our research specifically, but I highlight it because of my personal philosophy; the other two were major hurdles in our work.

- *To date, much PAR has been androcentric, led by male theorists and paying little attention to gender issues, although examples of a feminist influence are growing.*

In practice, our research found race to be the overarching influence, with class, gender, and age as important but secondary variables. Even though gender differences clearly played a part in these grandmothers' lives, their analysis of problems gave priority to the racial and cultural disparity which cause Aboriginal people as a whole to suffer from oppression and discrimination. The grandmothers did talk of their subordinate position in relation to men, especially their husbands, that developed with the loss of their traditional society. In contemporary Aboriginal society, "the 'gender issue' is simply that Aboriginal women continue to constitute the most aggrieved and oppressed constituency within Aboriginal communities."[284] But the grandmothers also talked of their central role in the whole family unit, and their authority and responsibility for supporting their children and other family members. Aboriginal women confront the same fundamental threat as their men: sheer survival.[285] And while women worldwide acknowledge facing common problems, Green maintains that "for Indian feminists, every woman's issue is framed in the larger context of issues pertinent to Native peoples"[286] such as self-determination and treaty rights.

126

In the first year of the project, the staff were frequently asked by Aboriginal men, "What of the grandfathers? Why can't the grandfathers be part of the project?" The staff replied that the grandmothers deserved special attention because they had not received it in other initiatives. When we talked about securing long-term support for the project by building partnerships with other groups, the grandmothers were adamant about wanting to avoid relationships with Aboriginal political organizations. They saw these groups as being dominated by men, and not meeting the needs of grassroots people but rather, as serving the politicians' own ambitions. They feared the project would lose its focus on them if it were associated with political groups, and once again women would be forgotten. Aboriginal society has developed a middle class which is almost exclusively male and exerts control over grassroots people. Yet as a female middle class develops, these women will have to be accountable, as well, to their people at large.

Our research, however, focussed on a group of women and on unique health issues which they viewed as principally influenced by race.

The next challenge refers to the capacity of the oppressed to be involved in PAR.

- *Because of its emphasis on unequal power relations, PAR is often used with oppressed groups who may not (i) have the capacity to devote to any endeavor which does not deal with basic survival needs, or (ii) be represented by an organized body with whom a researcher can work.*

In our work, most of the grandmothers lived on a low income which came principally from social assistance sources--welfare, old age pension, guaranteed income supplement, government pension plan, or worker's compensation; only two of the core, active grandmothers had an employment retirement pension. In general, their income was enough for a simple but adequate individual lifestyle. They became deprived, however, when their children or grandchildren took money from them, or when it fell to the grandmother to support others.

Usually, the irregular attendance at our weekly group was the result of grandmothers being involved in basic survival activities for themselves or their family. For many, their lives consisted of one crisis after another, and effort was expended in coping and surviving, with little left to participate in any research or other initiatives. When we were together, the grandmothers loved to laugh and have fun. As Barndt[287] observes, "people's priorities are often survival and entertainment above serious discussion."

Prior to our project, the grandmothers were not represented by a group with whom to work. Much of the first year of the project and research was spent building a group; nurturing it was an ongoing task. This group-formation was another key factor in the time it took to conduct the health assessment. We had to work very slowly, building a sense of cohesion and identity, before we could involve the grandmothers in PAR. Theoretically, the staff and I knew that the group-building process was essential, time-consuming, and long-term. Yet we still set unrealistic expectations about the grandmothers' capacity for being more involved in and taking control of the project and research. Continually, we had to reassess our expectations and activities to be more realistic.

The third challenge places PAR initiatives within the social justice movement as a whole.

- *If the analysis of the socioeconomic and political elements of the problem under study shows that they are, in fact, unchangeable, the analysis may heighten the research participants' frustration and dissatisfaction with the status quo, with little apparent resolution in sight.*

Our efforts to build community and raise consciousness about health-related issues coincided with other initiatives to increase the control that Aboriginal people in this city, province, and country have over their own health, social, and governance affairs. There are still many barriers and any change will be slow in coming, but there is an environment of

128

some will and negotiation, and a sense of justice in Aboriginal claims. As Jackson[288] reminded us, however, new knowledge and awareness are not enough to change government policies and services.

The grandmothers' project was funded for three years of development only, and no ongoing funding was secured other than for a year of work with a different focus by our coordinator. At project's end, the grandmothers experienced another example of being let down by "the system," an all too familiar experience in their lives.

These three challenges, PAR's androcentricity, the oppressed's limited capacity to take on a research function, and the possibility of an unchangeable context are significant hurdles for PAR initiatives, including our own.

Expected Results

This section looks at our health assessment research against health-promoting outcomes[289] that PAR might achieve, as introduced in Chapter 2.

- *Enriching data through the use of expertise in research subjects regarding problems studied.*

The data we collected over the 2.5 years of doing the health assessment were, largely, the grandmothers' own opinions, ideas, and experiences. The overall analysis and technical organization of the health report were done by me, but the grandmothers validated everything, ensuring that the full and correct intent of words spoken was presented in the written report. Their words were powerful and rich.

- *Raising, in the minds of the subjects, questions they might never otherwise ask themselves.*

When appropriate, during the interviews or group discussions, the staff, research associates, and I asked probing questions to encourage critical

analysis by the grandmothers of their experiences and opinions. Even though the debate and dialogue were limited compared to what might be achieved with other groups, we pursued topics more thoroughly than the grandmothers would have done before. In the project as a whole, we purposely drew the grandmothers into situations where they would study and question aspects of their lives.

- *Giving the powerless a voice and creating opportunities for that voice to be heard beyond their group.*

The project fostered the building of community among the previously isolated grandmothers and encouraged them to talk among themselves and as a group to others about their concerns and beliefs. The health assessment created a structured process and opportunities for the grandmothers to have a voice on health issues, and to document and disseminate a picture of their own health. There were numerous examples of their voice being heard, as described in section 4.3.

- *Establishing processes that link up people who never normally speak to each other.*

The project and research linked up grandmothers who were not already in touch with one another. Also, the grandmothers formed connections with many individuals and groups beyond themselves, for example, an intercultural group of grandmothers in the southern part of the province, staff at the sponsoring community clinic for whom they did in-services on Aboriginal people's health beliefs, and the provincial social services minister. The research was specifically responsible for guiding the grandmothers into certain engagements, such as the health district consultations which led to their permanent role on the Aboriginal subcommittee, and their work with activists against uranium waste storage.

- *Moving from "power over" to "power with."*

This shift occurred at various levels for the grandmothers. For example, the health care system, previously viewed in a position of "power over" the grandmothers and their families, moved further into a power-sharing position with the grandmothers principally through their increased understanding about and voice on the Aboriginal subcommittee of the health district board. At another level, most grandmothers increased their function and participation within the project and research. Rather than deferring to the organization and direction of the staff and me, they gradually took over group and task functions, moving to a "power with" position. To varying degrees, they made this shift within their families and communities, and in relation to other agencies and structures.

- *Linking research with community action and change.*

This was deliberately fostered through the health assessment, both in principle and in practice. At every feasible opportunity, as individuals and in a group, we took action on issues that arose. Furthermore, the grandmothers used the health assessment report as a resource document for a community workshop on their values which was held a year after project closure.

- *Establishing ongoing processes of community change, activating /mobilizing/empowering individuals and communities.*

Since the project funding finished, the processes for ongoing community change occur through the grandmothers' continued participation in other groups and initiatives that have ongoing resources, and through the efforts they can manage on their own, now that they feel more like a community.

- *Developing research skills in, and transferring other resources to community people.*

The grandmothers learned about research through being involved in their own health assessment. They gained added prestige and profile

through the publication of the report. They would not, however, in their present structure and on their own, be apt to launch research on another question. Yet likely they would look favorably and with more confidence and competence at participating in another research venture as part of a team. If they were asked now about their views on research considering their experience with the health assessment, conceivably they would describe it in more constructive terms. Further skills were acquired by the research associates and staff who were involved in the theory, development, and organization of the research, and who would be capable of actively participating in a subsequent initiative. Partially because of the model of our work, two other community groups used PAR in their own socio-health research.

- *Writing research results in different languages for different audiences.*

The written report of the health assessment research was written in English, but in the grandmothers' own words, either in direct quotations or paraphrased. The nature of the report was substantially different from a conventional needs assessment report. Ours was an attempt to capture the grandmothers' personal and collective experiences and ideas about their health-related resources and concerns. The format is "friendly" with photographs illustrating themes and reminding the grandmothers of highlights throughout the project. The language is accessible to the grandmothers and other readers.

- *Taking information and results back to, and for ownership by, the community.*

The research was a continuous process of taking emerging information, revised data, initial conceptualization of major themes and sub-themes, and drafts of the report back to the grandmothers individually and in a group. All the grandmothers received copies of the final assessment report, as did related community and Aboriginal organizations.

Our PAR experience did result in many health-promoting outcomes for all participants and for them in relation to the larger community (see more in section 4.3).

4.1.2 Points of Tension and Lessons Learned

This section is a synthesis of a number of challenges, constraints, and points of tension that arose in the project and in the experience of using PAR to do the health assessment: external control of project; external research decision; research stigma, focus, visibility, and resources; cultural traditions; project approach; research associates; participants' capacity, interests, accessibility, and articulateness; the nature of dialogue; and conflict resolution.

When taken separately, each point describes a challenge faced in our PAR practice. When sifted through the model of dialectics (introduced in section 2.2), the points were seen to be tension dialectics with elements which "appear to be opposites and interact in tension."[290] Rather than looking at these situations as "either/or," "right or wrong," "success or failure," they are viewed as forces acting in relation to each other. In this section, the dialectics in the project and research are discussed and also shown graphically[291] with arrows to depict oppositional characteristics and a discordant line in between to portray interactive tension.

The first two points, external control of the project and external research decision, demonstrate factors important in developing ownership of research by participants and the consequences of their absence.

External Control of Project

It is commonly said that community groups, especially oppressed ones, do not display sufficient interest in participating in research, thus the impetus and control need to come from the outside. There are differing views on this. To the oppressed, daily realities may not be seen as problems to be resolved; they are either simply part of life or are not

133

perceived as resolvable. To stimulate an inquiring stance and role, participatory techniques may be employed by outsiders to engender collaboration. Gainotten and de Wit, however, label these techniques "manipulative"[292] and claim they are not necessary provided the community group is responsible for the research. Nonetheless, oppressed groups may not have the resources available to be responsible for anything that does not contribute directly and immediately to their daily survival.

In our case, the project and the research were not the ultimate responsibility of the older urban Aboriginal women--advisory committee or grandmothers--but of others: the funders who were implicitly suspect because they were government; and the sponsoring agency, a health clinic previously familiar to very few of the grandmothers. There was tension over who controlled what. The advisory committee of the first year of the project did not have legislative authority. The coordinator and outreach worker tried to be accountable to the wishes of the grandmothers as well as the regulations of the funders and director. The grandmothers did not necessarily want responsibility for many aspects of the project but sometimes wanted the authority to make decisions about matters they did not control. Idealistically, in the true spirit of community development and PAR, the staff and I wanted the grandmothers to be in charge of the project. But they were not given the resources or authority to do so.

agency in power/control 〜〜〜〜〜 agency wants to empower grandmothers

advisory committee and
grandmothers want
authority

advisory committee and
grandmothers don't want
full responsibility
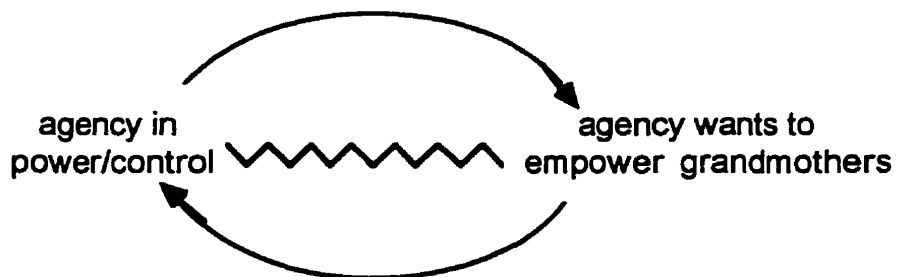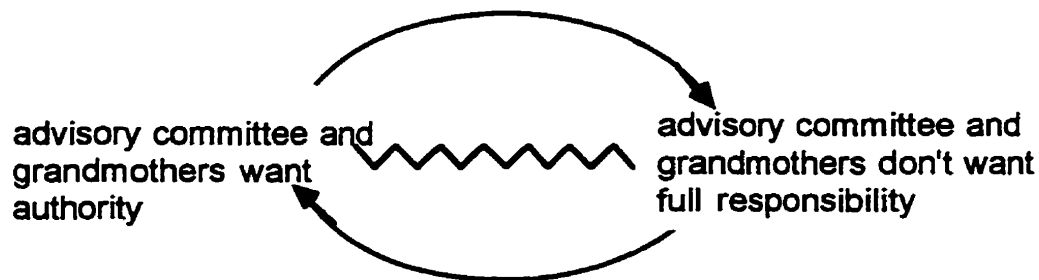
External Research Decision

A second ownership factor was a fundamental weakness that influenced
our entire process--the decision to conduct a health assessment was made
by the project planners and funders, not by those with whom and by
whom this was to be done. The director reasoned with the other staff,
advisory committee, and grandmothers that the assessment was an
essential aspect of the project being funded and would be a concrete
product at the end of the project for further programming. Although
they appeared to see the logic in this and agreed to it, they did not deduce
that an assessment was a logical, useful, and important thing for
furthering the grandmothers' well-being. No matter how rational the
arguments were, they were imposed. These three groups never fully
embraced or took ownership of the assessment, and their measured
involvement reflected a qualified commitment. I always felt the
involvement of the advisory committee and grandmothers in the
assessment was based more on compliance than on their belief in its
value. The momentum of the needs assessment was due more to the staff's
and my efforts than to their own interest in it.

Since my involvement in the project was to fulfill the research portion of
my doctoral program, I had a vested interest in seeing that the assessment
went forward. Despite realizing that the advisory committee and
grandmothers were being persuaded of its value, I sincerely believed that
doing the assessment using PAR would be illuminating and beneficial to
all involved--which is the reason I am committed to this paradigm and
methodology. Furthermore, pragmatically and honestly, I was not going
to be critical to the extent that it would undermine the initiative.

135

funders and agency
make research decision ⋁⋀⋁⋀⋁⋀⋁⋀ staff and I try to develop
ownership of research in
advisory committee and
grandmothers
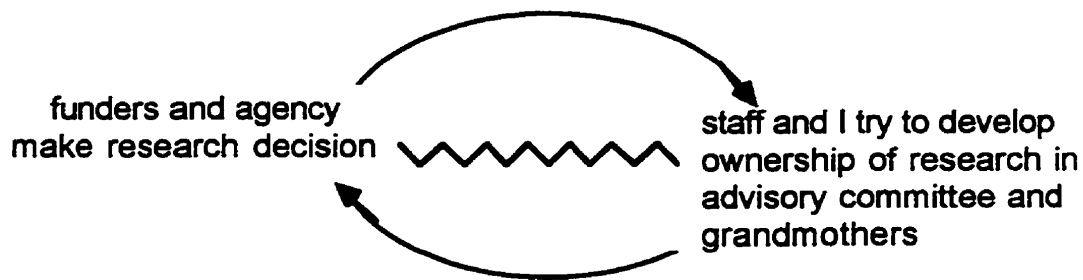
The next four points--research stigma, focus, visibility, and resources--
speak to difficulties of research in general with Aboriginal people and to
our process in the grandmothers' health assessment.

Research Stigma

The stigma of research was an area of tension that affected the health
assessment initiative.   Not many of the grandmothers had been
personally involved in a research study, but almost all would say that
their people have been researched to death and got nothing out of it.   It
was a commonly held belief that Aboriginal people had been studied
excessively by others but they were no better off than they ever had
been, and it was the researchers who had profited at their expense.   It was
difficult for the grandmothers to view any kind of research as being
under their control and for their benefit.   From land use studies in
northern Canada, a Dene writer comments:

. . . We know from past experiences that government research by white
researchers never improved our lives.   Usually white researchers spy on
us, the things we do, how we do them, when we do them, and so on.   After
all these things are written in their jargon, they go away and neither
they nor their reports are ever seen again.[293]

In a recent participatory research project on diabetes with Haida people
in British Columbia, Herbert[294] found a similar view of research based on
the people's past experiences.   The community perceived researchers as
"parachuting" in, taking samples, and disappearing with nothing of
value coming back to the community.   From St. Denis's[295] experience
with participatory research in an urban Alaska Native community, she

now wonders if research could be called a "service" and thus find more acceptability with Aboriginal people.[296]

The purpose and approach of PAR can ameliorate both the perception and reality of research as exploitative through an explicit focus on participants' empowerment and their control of the process and results. The stigma, however, affected our work throughout the project period. It took six months of relationship-building among the grandmothers, staff, and me before the staff began to introduce the words "research" and "health assessment." For the duration of the project, the words always needed some qualifying explanation to be accepted.

```
  research                    research
as exploitative  VVVVVVVV   as empowering
```
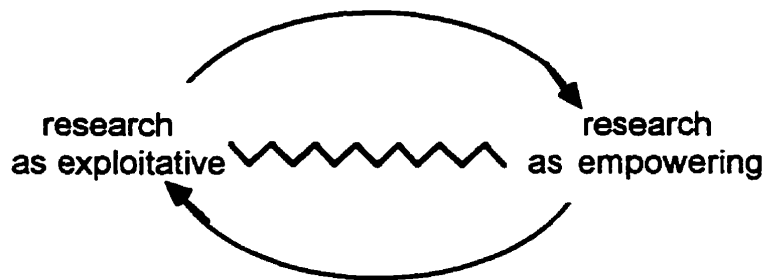
Research   Focus

The conventional focus of health assessments on needs and problems was deterring the grandmothers' participation and was not how they wanted themselves portrayed. Within the group and among themselves, they were willing and anxious to share their difficulties. When speaking of the injustices and disadvantages of their people as a whole, some learned to speak up publicly. But when formally and directly interviewed about personal problems or asked to be involved in a process that would focus on and expose the painful parts of their lives, they resisted. They were living daily their own personal dramas of hurt and shame. They did not want these to be replayed another time for another audience.

Maguire wrote of two relevant findings from her initial individual interviews with battered women in New Mexico. Although she "began by asking the women to talk about problems they experienced in their everyday lives, they began somewhere else . . . with the violence they had

137

experienced and survived. . . . Then without being asked, they talked about what was going right in their lives. It seemed important to identify not only their problems but also their successes and strengths."[297]

Park[298] identifies several reasons why oppressed people may find it difficult to speak openly about the problems in their lives: being unaccustomed to speaking in public; feeling intimidated by fear of offending those in power who are implicated in their difficulties; feeling ashamed to admit their problems, possibly indicating some responsibility on their part for their conditions; denying their own suffering in a sense of fatalism; and being unable to identify and label what lies at the core of their problems, all the while feeling their deprivation and oppression acutely.

Freire distinguishes clearly that the problem-posing he emphasizes is intent on doing a "critical analysis of a problematic reality"[299] and not a scrutiny of people as problems. He cautions that "the real danger of the investigation . . . lies in the risk of shifting the focus of investigation from the meaningful themes to the people themselves, thereby treating the people as objects of the investigation."[300] He emphasizes the "necessity of posing as problems the myths fed to the people by their oppressors"[301] so their reality is seen as something to be demystified and challenged, not themselves.

In retrospect, I see that I could have been more directive, clear, and articulate about steering our dialogue to the grandmothers' troubled reality and away from any intimation that they themselves might be problematic. A sharper distinction might have allayed their reluctance to explore the distressing aspects of their lives. For the grandmothers, what they were willing to share and contribute directly to our health assessment were those aspects of their lives of which they were proud and would show them at their best. Once those parts were expressed and documented, the grandmothers allowed the other more disturbing material, which I had gathered indirectly, to be included so that a balanced picture could be given in the report.

```
     ┌─────────────────────┐
     │                      ↘
health assessments'          grandmothers resist
focus on problems  ∿∿∿∿∿     problem focus
     ↖                      │
     └─────────────────────┘
```
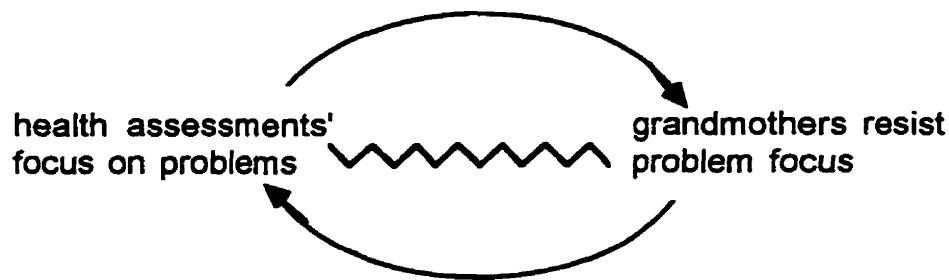
Research   Visibility

Because the research was so well integrated and compatible with the
other project activities and spanned the life of the project, it was hardly
seen by the grandmothers as a distinct initiative.   Its effective
integration demonstrated the research's congruency with the rest of the
project, but also made it barely discernible.   The health assessment report
helped to clarify the research by putting a concrete and tangible face to
it, but it described the findings and not the process.   This lack of clarity
on the research process may hinder the grandmothers from sharing
their experience with others, formally or informally, and from
replicating their experience themselves with a different research
objective.

```
     ┌─────────────────────┐
     │                      ↘
research compatible          research indistinguishable
with project      ∿∿∿∿∿      from project
     ↖                      │
     └─────────────────────┘
```
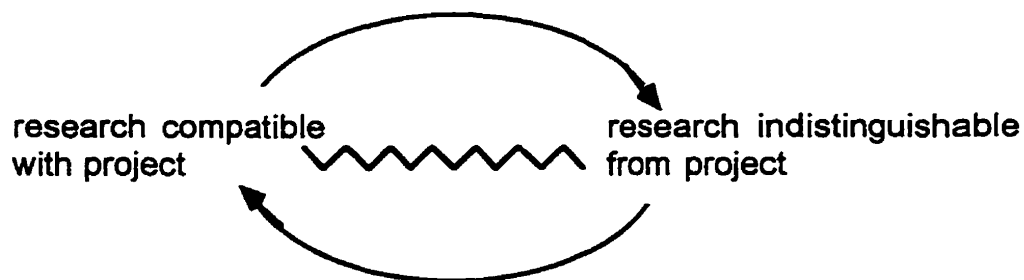
Research   Resources

In order for PAR to be effective, essential and adequate resources must be
available--notably time, funding, and skills.   Other mainstream research
requires these resources, but since PAR is seen as a "grassroots"
approach, it may not be seen as needing the same level of support because
it is done largely by local people themselves.

The pace at which PAR can proceed depends on many things but it must allow for enough time to build trusting relations among the research team, to conduct the research, and to act on issues arising. The time needed was problematic not only because of the restricted project time frame but also because participants' time was limited by their daily schedules of work, meeting survival needs, and their desire for socialization and recreation. Maguire called time "one of the most underrated limitations on participatory research."[302] External researchers must be able and willing to commit an extended period of time to their involvement. For example, the Big Trout Lake Band environmental assessment, working with the Participatory Research Group in Toronto, took ten years to complete research on water and sewage alternatives.[303] The band concluded with a decision to build a system which serviced all houses in the community, rather than the one initially proposed by the federal government which would have serviced only a small minority of non-Aboriginal residences.

Cancian and Armstead point out that notable change often requires sustained resources and a vital community group, neither of which this project could maintain when funding ended. Most of the ongoing, post-project action was that in which the grandmothers were involved with other groups which had sustained resources to continue, such as the Aboriginal health district subcommittee and a child policy and advocacy coalition.

Funding, or other in-kind support, is important, especially with oppressed and marginalized people who already have less than they require for their basic needs. For our grandmothers to work together, they needed transportation, meeting space, and staff organizing support. My time, which was 2.5 years of near full-time involvement, was at my own expense but otherwise the contribution of an external researcher may have to be subsidized.

PAR seen as "grassroots" research requiring few resources ⟷ PAR requires substantial resources
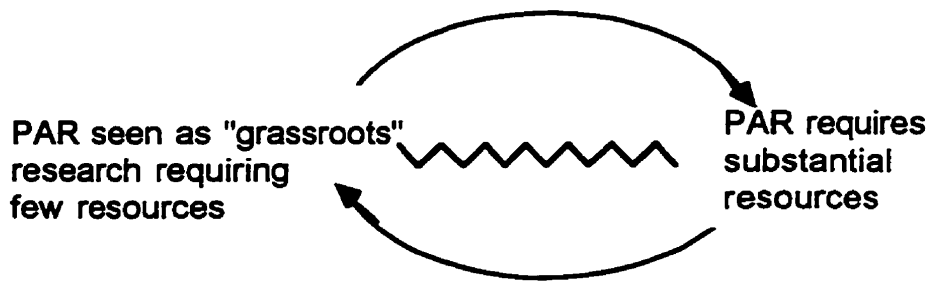
The following point of tension is specific to our group but would be common to other people subjected to cultural invasion.

Cultural Traditions

Oppressed peoples' self-worth and capacity to work on their own behalf are enhanced by "re-searching," retrieving, and reestablishing their meaningful and effective cultural traditions.

Despite the differences within the grandmothers' group, it was evident, more so in retrospect, that the cultural aspects of the project were highly valued by the grandmothers--healing circles with smudging and speaking stone, traditional feasts, ceremonial planting of a tree at a nearby historical site, and occasional involvement by elders. Our emphasis on Aboriginal culture was tempered by a minority of grandmothers who had been imbued with Christian dogma and a distrust of traditional beliefs and rituals. Looking back, our coordinator believes we should have continued with the traditions for the benefit of the whole group, despite the objections of a few.

value of use of cultural traditions ⟷ minimal use of traditions due to criticism

141
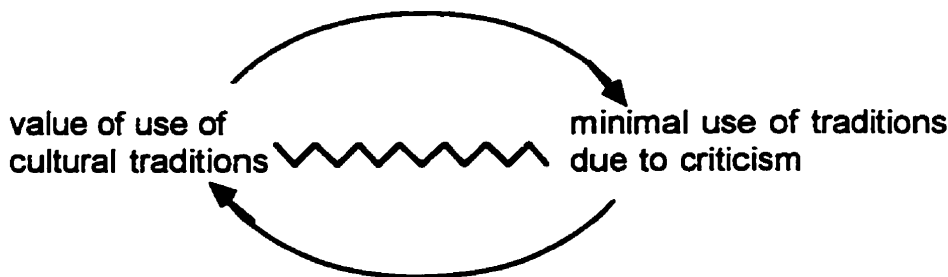
This next point speaks to the dependency dilemma common in community development projects--how much intervention is supportive and how much defeats self-reliance.

Project Approach

Within and between staff and grandmothers, there was tension about the role and function of the project and staff in relation to the grandmothers--how much support should be provided to the grandmothers to participate in programming activities and how much should the grandmothers be using their own initiative and resources. In principle, the project was explicitly committed to fostering the independence and self-reliance of the grandmothers. This was played out, for example, by encouraging the grandmothers to take on responsibility for organizing project activities, recruiting and supporting new grandmothers, representing the project on external committees without staff support, and getting themselves to the Tuesday get-togethers instead of relying on staff pick-ups. These efforts met with limited success, however, with some grandmothers assuming more responsibility and others less, and in some initiatives and not in others. This measured responsibility demonstrated the complexity of community development with this group in this project. Since the project was not of their instigation and not under their control, the grandmothers viewed it as not wholly theirs. It was something they took part in regularly, but was run by the staff for them.

Self-reliance in the project was off-set by a service mentality on the part of some grandmothers and staff. Despite our ongoing discussions of personal and community development, some individuals resolutely thought that ours should be a service project because, as one staff member put it, that was what these older women needed and deserved. Other government or Aboriginal initiatives the grandmothers had been part of had been of this nature, providing services of various kinds which created dependence, and to some extent that is what they expected of this one.

142

Additionally and admittedly, the staff and I wanted to "do for" the grandmothers at times. We recognized that they functioned as caretakers of others most of their lives. Our project was a unique and singular experience for most of them to be cared for and catered to themselves, and thus we felt justified in treating them to little favors and pleasures. Did this create dependence or did it enhance their self-worth? It was a question we debated.

project supports and caters
to the grandmothers
project aims for
grandmothers' self-reliance
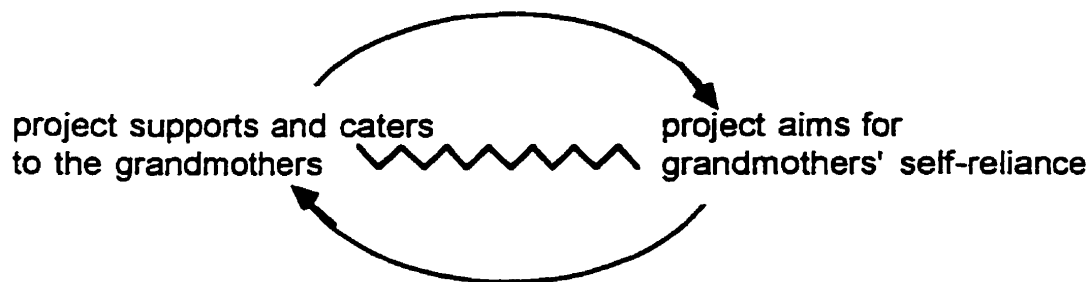
The following point addresses the challenge of introducing employment to enhance the capacity of the research team.

Research Associates

The research associates' term with the project had benefits which advanced the health assessment, but there were also difficulties and strains. The choice of the two hired candidates was later criticized as nepotism by a few grandmothers because of their relationship with the coordinator.* Their work habits deteriorated over time and issues related to their chronic personal debt affected their performance and our relationship, the public domain of their employment being affected by their private limitations. The work of one was incomplete and of poor quality, and her attendance unreliable. The grandmothers knew more about what was going on than I did but only later did they tell me. As with other areas of difficulty, they avoided talking about it openly, but did talk among themselves. Despite these restrictions, the employment of the research associates gave higher profile to the health assessment with the grandmothers, the individual interviews they conducted were affirming experiences for the grandmothers who took part, the two trainees learned something about research which may serve them well in the future, and

because of concern for their work I developed more confidence in my ability to work directly with the grandmothers in furthering the health assessment.

associates enhance research visibility and scope

associates are burdened with personal problems and their work suffers
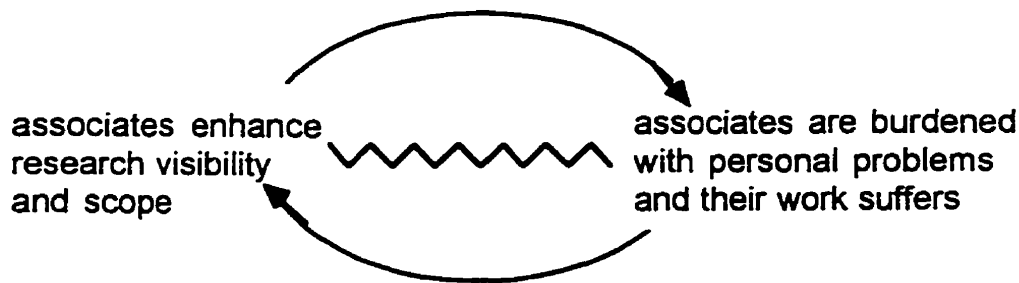
These next four points refer specifically to the unique situation of grandmothers as primary co-researchers: their capacity, interests, accessibility, and articulateness.

Capacity of Participants

A factor which had a major impact on the grandmothers' ability to profit from and contribute to the project and research was their limited capacity to absorb resources and take advantage of opportunities.† Their own health, family and social obligations, and personal histories restricted their ability to be active and take on extra responsibilities and involvements.

Being oppressed women, living on the margins, meant that the grandmothers had "to perform a kind of doublethink/doublespeak in order to translate [their] experience into the concepts and language of the status quo."[304] Audre Lorde, a Black, feminist, poet writes of the challenge and toll it takes to live as a disempowered woman:

> . . . traditionally, . . . it is the members of oppressed, objectified groups who are expected to stretch out and bridge the gap between the actualities of our lives and the consciousness of our oppressor. For in order to survive [we] . . . have always had to be watchers, to become familiar with the language and manners of the oppressor, even sometimes adopting them for some illusion of protection.[305]

144

The grandmothers were offered an array of activities by interested individuals and initiatives in the community that quickly saturated their available time and energy. The staff and I had to constantly moderate our own expectations of what we could involve the grandmothers in, and play a screening role in relation to other groups who wanted the grandmothers' counsel and participation. Although we recognized this as being custodial, we felt it was the only thing to do to avoid having the grandmothers swamped with requests. The potential for their contribution to various initiatives far outstripped their actual ability to do so, given their other personal responsibilities.

Within any particular project activity, consistent participation was a real challenge. Because of their limited capacity, most grandmothers were irregular in their involvement in any one initiative at any stretch of time. This affected the progress of our health assessment to a large extent. Because this was participatory research, it was important that everyone accompany the development of the assessment. Discussions held and decisions made at any one Tuesday morning, however, could not serve as a base for advancing the topic the next week, because inevitably the composition would be different, as it would be the week after that. A summary review at the next meeting would still not reach everyone and, further, would be inadequate for the grandmothers' full understanding. The grandmothers' approach to learning and participating was generally through slow and steady incremental thinking which was interrupted or halted if they missed sessions where steps were covered. To reduce this loss, I repeated many explanations and material in group, and occasionally, briefed individuals in their homes. Even so, it meant that not all grandmothers were always well informed on the process.

grandmothers are in demand, a source of wisdom, interested in activities and issues ⟷ grandmothers' capacities are limited by poor health, family demands, and lack of resources
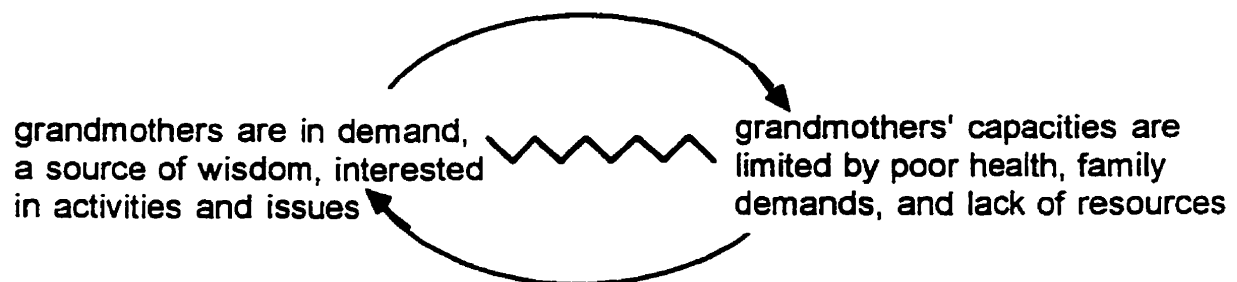
Interests of Participants

The grandmothers were most interested in project activities that were social, enjoyable, and interesting. In earlier years, a few had been in Aboriginal women's organizations, on problem-solving committees with their employment, or in community initiatives. They felt they had made their contribution, and now it was time to lead a less work-oriented and stressful existence, if possible. Others had no experience being in a group, working on committees, or being involved in any community activity. Most would have been content to take part in healing circles, listen to some educational speakers, take field trips, plan special occasions like feasts and dinners, and visit and drink tea with one another. Other efforts like the health assessment, active participation in community committees, lobbying for policy change, and so forth were seen by many as work and were not the involvements of choice by some.

Maguire found similar responses in her research group of formerly battered women in New Mexico. As she tried to wean the group of her own organizational role, one of the most active members described her own reluctance to take anything on. "I like having something I can just come to and get something for myself without having to worry too much about it."[306]   Others agreed and spoke of their child-raising and work responsibilities, the ability of Maguire herself to continue the organizing, and the benefits of their group having to be weighed against the time costs of their control of and participation in the project.

community, project, and research have high hopes for grandmothers' involvement in their initiatives

grandmothers want healing, socializing, and fun, and resist more responsibility
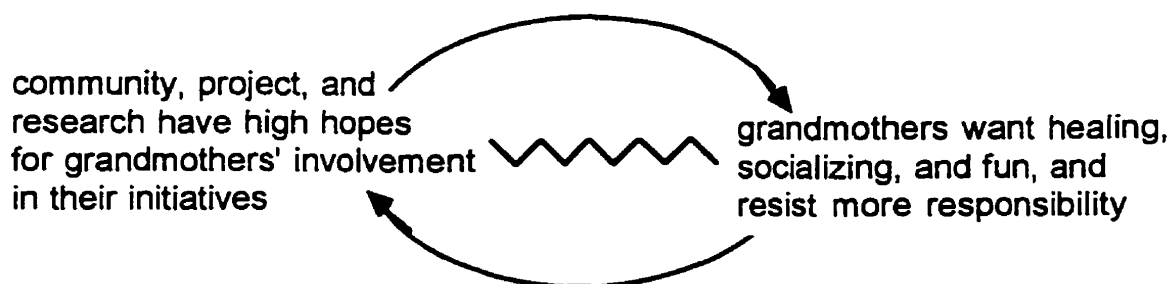
Accessibility to Participants

Accessibility to the grandmothers was one of the greatest constraints of our research. The project and research had limited accessibility to them because of the many competing demands on their time and attention, including attending to their families' needs and their own poor physical and emotional health. Maguire also found that "while researchers may be able to invest their total work time in a participatory research project, participants continue their regular activities."[307] de Roux, in describing a PAR experience of Colombian communities in negotiating electrification of their area, observed, "The research initiative had to be carried out amid the vicissitudes of the community's pace of life, which did not come to a halt to accommodate the research."[308]

I had limited accessibility to the grandmothers for working on the health assessment together because of the many other competing programs and activities within the project. In the second and third year of the project, when the assessment was being worked on actively, several weeks could go by between any time available for it. Inevitably, there was memory loss by the grandmothers and staff on what we had covered, and even what this initiative was about.

research proceeds only with the participation of the grandmothers

research slowed and stalled by limited accessibility to the grandmothers
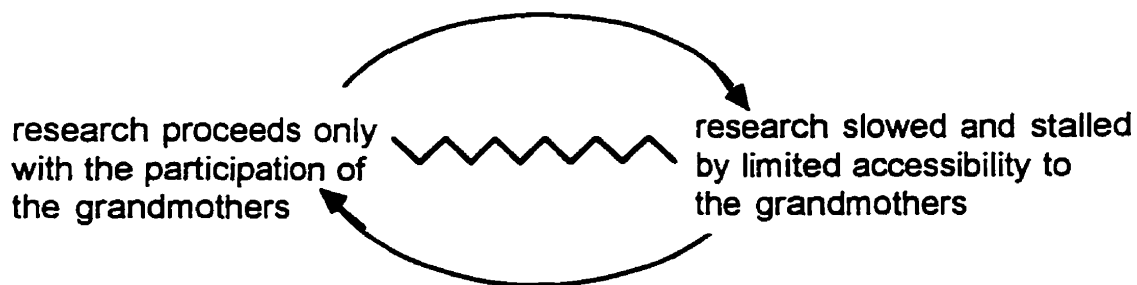
Articulateness of Participants

For most of the grandmothers, English was a second language to their own native one. Also, many were unaccustomed to expressing their ideas, opinions, or feelings through words of whatever language. Within the project, nonverbal ways of communicating were as or more important as

verbal: laughter, hand shakes, hugs, and empathetic eye contact. Yet speech was the primary method of communication used for discussion of an issue, stories of their past, expression of beliefs, description of their concerns, and hopes for the future. The grandmothers' words were the principal type of data I used for their health assessment report, and for assessing the impact on them of their participation in the project and research. The dependence of our research on verbal expression for an accurate picture of the grandmothers and our work together was a constraint. I knew they would want to, and could, offer even more than they did if they had the vocabulary and fluency to match the rich experiences of their lives. As one of the grandmothers said, "Aboriginals sometimes in group are misunderstood because sometimes it's hard to put into words what we really want to say."

grandmothers have much to contribute and others want to hear

contribution of grandmothers is restricted by their limited fluency —vocabulary and practise
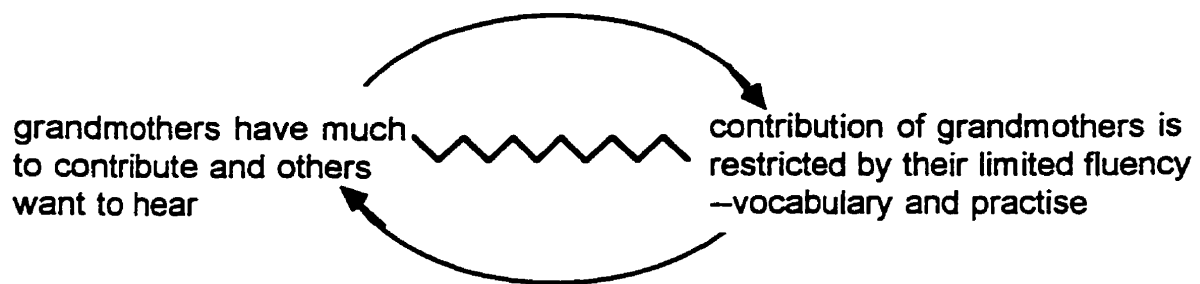
This next point discusses the unique nature of dialogue, a central concept of PAR, as played out in our research.

Nature of Dialogue

Dialogue is a fundamental characteristic of PAR, and PAR is "dialogical research oriented to the social situation in which people live, attempting to organize them and to break up the subject/object binomial."[309] PAR requires intersubjectivity, "an authentic dialogue between all participants in the research process in which all are respected as equally knowing subjects."[310]

In what Freire coined "problem-posing dialogue," the external researcher asks such questions as "Why is there poverty?" or "Why is there oppression and dependence?" By responding to such questions,

148

people in the community may gain greater insight into their situations and may feel the need to find out more through research and take political action. "It is not just so they can reveal private facts that are hidden from others but really so they may know themselves better as individuals and as a community."[311] Freire concedes, however, that most people are conditioned to accept their reality rather than examine it, and may choose not to deepen their knowledge "through patient dialogue with others."[312] He advises that when this is the case, first respond to the expectations that the group has, then give them the knowledge they are seeking but begin to challenge them: "What are your reasons for asking this?" By so doing you are again returning to a critical understanding of the situation. You are trying to enable them to understand their request."[313] For example, when the grandmothers asked for an educational on stress, the staff complied by setting up a speaker on that topic. To look at their own stress, though, we could have found the time first to encourage them to explore their own reality more deeply than they normally viewed it, and gradually develop familiarity with this kind of analysis.

The advisory committee responded to problem-posing questions with an expressed interest in finding out more about the health of older Aboriginal women of which they were part. With the committee's dissolution, however, it did not pursue this inquiry.

Because of the grandmothers' aversion to speaking about problems directly, their conditioning to accept their lives as determined by others, and the restricted time devoted to the assessment, we had limited opportunity and success building comfort and expertise in critical social analysis. Whenever I had a chance to ask probing questions, a few replied perceptively and the rest appeared not to understand. Naming, examining, and debating structural causes of problems was part of what they would label "Indian politics." The grandmothers wanted no involvement with politics which they viewed as laden with patriarchy, conflict, and exploitation, and counterproductive to their own well-being.

Maguire also found that the participants in her research, formerly battered women in New Mexico, "didn't develop a structural analysis of patriarchy, capitalism, or racism, [but] they gained a more critical understanding of the problems they face 'as women' and a better understanding of battering as an expression of male control."[314] Our grandmothers, too, became better informed about systems affecting their lives, including health, social services, and civic government, and developed a clearer understanding of influences and determinants in their reality.

The traditional Aboriginal manner of dialogue was for people to speak one by one in sequential fashion around a circle. Their more common lived experience, however, was being silenced--at residential school in their own language, in society as racialized poor women, and at home in unsatisfactory relationships. These women were not accustomed to articulating their feelings, opinions, and experiences in detail and depth. Further, Fals-Borda (1980) observes that being oppressed gives people a distorted "view of their world and their own capabilities. The result for most is passivity and a resignation to the *status quo* as an unchangeable and natural experience."[315]

A fundamental dimension of the theory of oppressive action is "divide and rule." This approach was taken with Aboriginal people throughout their colonization and continues today with "the emphasis on a focalized view of problems rather than on seeing them as dimensions of a totality."[316] The grandmothers had little experience looking at their immediate problems as individual manifestations of larger power inequities, and we had only limited success achieving that vision. "The reconstruction of knowledge for the purpose of furthering social progress and increasing people's self-awareness with PAR *vivencias* takes dialogue as its point of insertion in the social process."[317] We would have needed more time together to develop comfort and skill in deepening social analysis through dialogue. Yet Maguire encourages participatory researchers not to underestimate achievements, however modest.

.

The temptation is to dismiss or underestimate our efforts because they do not appear long term, transformational, radical or important enough. The challenge is to celebrate our collective accomplishments, however small, and nurture ourselves as we move, however slowly and imperceptibly, in the direction of change for social justice.[318]

problem-posing dialogue
is key to critical analysis

traditional dialogue is
one-by-one in circle;
grandmothers avoid "politics"
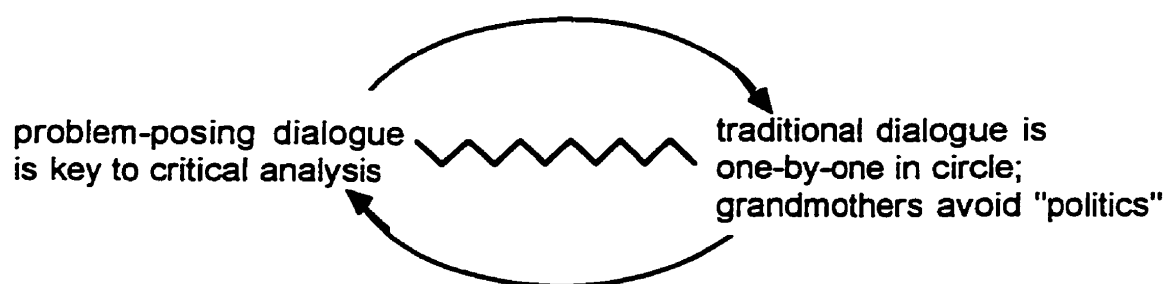
This final point speaks to an underlying dynamic--conflict--that influenced the community of grandmothers, the project, and our health assessment, but was best understood months after project closure.

Conflict Resolution

The personal histories of many of the grandmothers influenced both the degree to which they had trust in anyone and the style with which they dealt with others. Most had had difficult lives and their histories affected their way of expressing differences and handling conflict. Some were very passive and quiet, most were reluctant to express a point of view that might provoke debate and possible divisiveness in the group, and a few were confrontational at times. Within our project, we never did establish ways to resolve differences and problems and handle conflict, and this affected our progress and impact. It resulted in occasional tension in the group, loss of a few participant grandmothers, and a less effective healing circle for some when we dropped the ceremonial rituals.

Typically, the traditional Aboriginal approach to conflict resolution is to avoid confrontation and work around an issue by assuming that it will eventually be resolved, either through consensus-building or the withdrawal of the dissenting individuals. This pattern of dealing with conflict did not serve the needs of the grandmothers in our project because they were from varied backgrounds with some accustomed to

traditional ways and others familiar with those of the contemporary dominant system. In a cohesive community, social mores could achieve resolution of problems, but this was a newly forming group which occupied only a part of the grandmothers' lives and was without established conventions. As Brant Castellano noted about Aboriginal people in Canada, "Synthesizing diverse cultural perspectives with a tradition of autonomous decision making often makes united action problematic."[319]

Eight months after our project ended, our coordinator visited 14 of the grandmothers with some specific questions about conflict and its resolution so as to inform her new work with the more isolated elderly Aboriginal men and women in the city. She obtained the grandmothers' verbal consent to record and use their comments, and took notes by hand. Most of the grandmothers acknowledged points of tension and times of conflict during the project which were not openly dealt with at the time or later. When asked about their recollections of conflict, responses included:

> When [some] turn around and upset things . . . even when we try to get along with them, it does not work. Confrontation in the group would have become a shouting match; it's the last thing you want. I was always careful not to say anything. We were there to help each other and get along.

> In order not to cause problems in the group, I kept my mouth shut.

> At times, a person would bring up a subject but never completed the disagreement. This left the group hanging. Because of not knowing my culture, I just went along with the flow.

> Conflict started when money was involved in the group. There was a power struggle in the group. If the group had been together, it would have been powerful, but power went to some individuals.

> Conflict in the group caused some to drop out which should have never happened. Therefore, we lost some very valuable input for the group.

When asked about their experiences with conflict in other Aboriginal groups, some grandmothers had observations:

If a person is questioning conflict, they are made to feel
incompetent . . . an individual is left to take all the flak . . . no one
backs them up, then the others will come later and whisper their
approval.

We Aboriginals seem to lose focus in meetings . . . some come to
meetings with a chip on their shoulder. It seems like they voice
these chips whether it is appropriate or not. For example, a meeting
on housing is held. An individual will get up to speak on the issue,
and he or she will get angry and will start to speak totally about
something else. . . . Maybe some people are dwelling on the past too
much and can't get out of the hurting cycle.

[To] challenge in groups is not culturally appropriate. People
usually don't say anything. It is part of the culture to just walk away
from conflict. [If challenged], some Aboriginals . . . get very
defensive and shut you off with anger.

The coordinator asked about constructive ways to resolve conflict in an
Aboriginal way, and responses included:

I've seen [conflict resolved by] setting a time after the meeting to
discuss the conflict with the people involved who are usually the
chairperson and the disagreeing parties. Also an elder was used.

It's kind of hard to deal with it. As a Native person, I wouldn't want
to hurt the person as the hurt would linger maybe for life. It was
best to remain neutral. The healing circle, if we [believed in] it
individually, should have resolved conflict. If there was meaning in
the healing it would have been good, but some participants did not
believe in the healing process [of the circle]. Maybe that was our
downfall.

A good elder will discourage gossip, jealousy and violence. Elders are
nonjudgmental. They encourage you to resolve conflict in a
humanistic way using empathy and coming to a positive conclusion.
Elders . . . [say], You have to do it for yourself as no one else can do it
for you.

Perhaps more educational sessions in communication, relationships,
and spirituality would have helped the project. And [in the past]
elders in a group were very blunt with us and put us in our place.
They had a right to do this. Today, I'm not sure it would work.

When asked about what role a group facilitator could play to resolve
conflict, many grandmothers were not sure, but some offered differing
opinions:

.

153

> The facilitator should be able to control the situation and be a good listener. There should be no favoritism. The facilitator should not be perceived as taking sides.

> A more directive role [by] the facilitator would have got ugly and more destructive for the group. Perhaps it would have ended up that the person would have left the group.

> The facilitator has a leadership role but also the grandmothers have a responsibility of resolving the conflict. They should have been helping the facilitator when conflict occurred.

In relation to the dominant society and the dysfunctional parts of their own society, some of the grandmothers had learned damaging aggression to protect themselves and their children. Inevitably, the women brought their own personal dramas to the group which occasionally hurt relationships among us. Nonetheless, our project was trying to build a community that was neither threatening nor demanded dysfunctional conflict resolution approaches. But because we were not clear and explicit about how to deal with conflict, we had a few grandmothers withdraw from active participation to avoid confrontation, a few staying who started conflict and exerted more control and authority, and others who were silent but uncomfortable.

tension and conflict exist ⟷ conflict avoidance adversely affects project and research
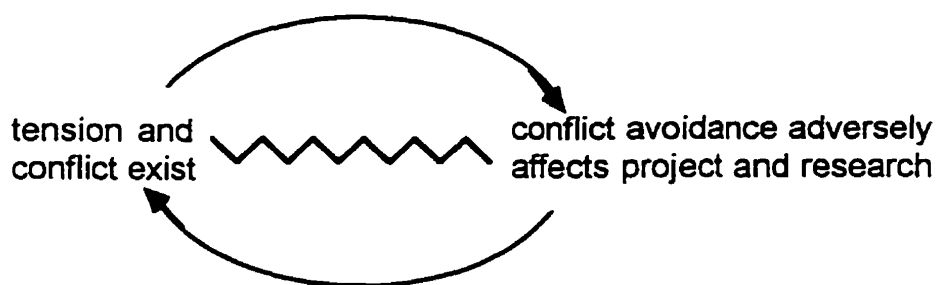
It is interesting to note, as did both the coordinator and I, how articulate and forthcoming many of the grandmothers were in their comments on conflict during these interviews. Evidently because the formal project had ended, there was no longer the risk of disrupting relationships in the group or of being blamed for being critical of the conflict. It was also easier to offer opinions privately and in confidence to the coordinator than to make them more publicly to the group. Perhaps, too, it was easier to see and understand the dissension almost a year later.

In this next and final section in "discussion and critical reflections on doing PAR," I identify process-oriented successes, and then use specific criteria developed by Fals-Borda[320] to examine our experience and identify accomplishments. This is not a definitive or exhaustive list by any means but is a way to highlight some of what we achieved through using PAR. More specific accomplishments are described in detail in sections 4.3 regarding the effects of participation on participants, and earlier in this subchapter under "expected results."

4.1.3 Accomplishments

From this practice of health promotion and PAR, there were a number of accomplishments. The process of our research is as noteworthy as the outcomes. The grandmothers:

- grew in their appreciation of themselves and each other as respected, knowledgeable, and valued members of our group, as Aboriginal people, and as part of the community at large;
- developed a sense of community among themselves and offered each other love, support, and a sense of belonging; and
- demonstrated their ability to advocate for themselves and on issues they deemed important for personal health and a healthy society.

Fals-Borda[321] describes useful ways to establish people's empowerment and countervailing power--collective research with its elements of recovering and documenting history, stimulating popular knowledge, producing and diffusing new knowledge, and valuing indigenous culture. In our work, we did conduct collective research which included to varying degrees those empowering elements.

Collective   Research

This inquiry process collected and systematized information gathered on a group basis. Heaney argues that people have been doing research

155

together from earliest times, and that the survival of our species depended on "an endless agenda for creating new knowledge"[322] over thousands of centuries. The survival of our species demonstrates that early research "must have been participatory--each person contributing what he or she could to the store of what was known."[323] Our research helped reclaim this collective, innate research process for use today.

In our project and research, the information the grandmothers articulated in our individual and group interviews, healing circles, and consultations became our data and objective knowledge. Our collective and dialogical methods produced data which was immediately corrected or validated and which was given social confirmation by the grandmothers; such affirmation would not be achieved through other individual methods. Documentation in the health report was one way for this knowledge to be passed on to others.

Critical Recovery of History

Through collective memory, we endeavored to identify those elements of the past which proved useful in the cohesion and capacity of the grandmothers' communities, and may be applied today. In this way, concrete information and other facts may be recalled that can correct, complement, or clarify popular beliefs and official accounts written from other perspectives or with other biases in mind. Moreover, drawing on the common memories of the struggles in which Aboriginal people participated reminded the grandmothers of their people's capacity to withstand colonization. "Traces of a once-authentic life that was tradition-bound but self-determined live on in the collective memory of the people sharing a common history."[324] Other PAR experiences[325] demonstrate the rediscovery of historical and cultural roots as an essential element in improving depressed communities. In our work, information recalled by the grandmothers was presented in the health report in the sections, "traditions" and "disruptions."

Valuing and Applying Culture

Culture is "the creation of spaces for men [and women] to meet each other . . . all the symbols of collective identity and memory: testimonies of what we are, prophecies of the imagination, denouncements of what impedes us to be."[326] Through individual reflection and group dialogue, the grandmothers, staff, and I identified essential and core values through stories of the grandmothers' cultures: past and present social norms, traditional beliefs and practices, crafts, food, recreation, medicines, spirituality and ceremonies; and dreams and their vision for the future. Valuing culture is done through "recovering people's practical skills, communal sentiments, ancient lores, and collective wisdom that lived on but were submerged." [327] The information on culture was written into the health report in both the first section, "traditions," and the last, "teachings, solutions, and hopes."

As mentioned earlier, the staff and I better realize now that use of rituals and ceremonies and the presence of a resident elder would have strengthened the project and research, grounding us more firmly in the history and culture of the grandmothers.

Stimulating and Validating Popular Knowledge

Knowledge which exists as local or indigenous science and wisdom was advanced by our research through its elucidation, affirmation, organization, and dissemination. This existing knowledge forms the base for new knowledge so that the latter is relevant and comprehensible to the participants. Gaventa argues for the inclusion of people's or peasants' knowledge because the experiences of oppressed groups, such as American Blacks and Aboriginals, "demonstrate the existence of cultures in which knowledge has not been fully absorbed by the dominant knowledge structures."[328] Kirby and McKenna maintain that "the primary source of information when researching from the margins is the people who have the experience you are seeking to understand."[329]

In the project and our research, stimulating and validating popular knowledge was specifically addressed in the healing circles, educationals, and the individual and group interviews. At all these occasions, the staff and I worked to draw out and acknowledge the grandmothers' own experiences, beliefs, ideas, and opinions, and then use these as the foundation for developing new knowledge. This existing popular knowledge was documented especially in the final section of the health assessment report, "teachings, solutions, hopes."

Production and Diffusion of New Knowledge

Production of knowledge is central to any research. New knowledge arose and was synthesized from the project and research indirectly through the interpersonal encounters and community opportunities, and more directly through the research interviews, analysis, and reporting. Diffusion of knowledge is related to the ownership and purpose of research. In PAR, the research process and knowledge produced is owned by the research team of community participants and external researcher. The purpose of research is explicitly for the participants' empowerment. Again, survival of our species demonstrates that mankind's "discovery must have been closely linked with dissemination--the group coming to know in dialogue and passing on accumulated knowledge to the next generation."[330] The health assessment was communicated principally through the report which incorporated both words and photographs, made as clear and accessible as possible, and distributed widely. Through the grandmothers' community workshop on values and participation on committees and in conferences, their knowledge continues to be formally shared with others.

This concludes the discussion and reflection subchapter on the PAR experience. Next, I examine the role of the external researcher in PAR.

4.2   Critical Reflections on Being the External Researcher

This section gives my reflections on being the external researcher (ER) in PAR based on my experience, including why this consideration is

158

important; how to get started; roles played; personal motives, supports, and benefits; challenges; and lessons learned. Already covered in section 1.3 are the assumptions about PAR and this research that I understood theoretically and held prior to starting the health assessment. My first attempt at PAR was curtailed early, as described in section 1.2. This second initiative, the participatory health assessment with the grandmothers, provided an opportunity for working through and learning about PAR in practice from start to finish.

This section is included with the other findings because the external researcher (ER) is an active presence and actor in PAR, and what is learned about that role was instructive for my own learning and may be for other readers. I recognize and acknowledge that I was not an impartial or unimpassioned researcher, and that I influenced how this research was conducted, what influence it had on participants, and how the findings are portrayed. My own experiences and values shaped not only my decision to study PAR, but also how I related to the grandmothers and staff, the emphasis we gave to empowerment, and my support for the research to evolve like the other activities of the project. To conduct this research, I invested part of myself and I was an ingredient of it. Rather than consider these elements as limitations to the research, I view them as enhancing the health assessment, the empowerment of all participants, and my development as a researcher. The diversity of influences served to enrich our knowledge and the growth of all involved.[331]

One of the aims of PAR is to create greater equality in the relationship between the ER and the participant subjects. This balance is enhanced by making explicit the external researcher's assumptions, motives, and values, rather than by the conventional exploration of the subjects' characteristics only. A dual contribution puts all participants on a more equal footing. Further, it helps to clarify what influence the external researcher will have on the approach and content of the research.

159

4.2.1 Getting started

Often one of the hardest steps to take for the ER is getting started. Maguire overcame her difficulty by following the personal instruction of Rajesh Tandon: "Participatory research principles are not purist. You can't sit and wait for the ideal situation. Waiting to do it right is paralyzing."[332]

It worked best for me to join in with general project activities, and play whatever role I could to launch the project, develop relationships with participants, and build the sense of group coherence. My profession as a nurse gave me an understood and respected label and function, and my early tasks included doing educationals on health topics of the grandmothers' interest. Most of my other involvement was group development and maintenance, such as transporting grandmothers, making coffee, keeping notes of our get-togethers, supporting the staff's facilitation, and joint planning with the staff. This activity would fall into what Ornelas calls a "bridge activity"--something short-term to help with entering a community, giving its members a chance "to size you up and get to know you."[333] In our project, the more immersed I got, at both a group and individual level, the more able I was to introduce and further the idea and initial steps of the participatory health assessment, at first with the advisory committee and staff, and later with the grandmothers. Ideally, the researcher already lives in and is of the community but I was not; therefore, getting involved in order to become known and trusted was critical, and took time and patience on everyone's part.

4.2.2 Roles

The roles an ER plays are many and varied. A special 1982 issue of the *Canadian Journal of Native Studies* acknowledged the role of ERs with Aboriginal communities in contributing "knowledge of the functioning of institutions of the larger society as they impinge on Native concerns while community members provide expertise in defining the issues and in culturally and behaviourally appropriate ways of addressing them.

160

Together both groups search for methods of linking resources to communities to solve development issues."[334]

The ER becomes a broker or mediator between local Aboriginal communities and institutions of the larger society. This implies being more than "passive channels of communication between cultures,"[335] and involves exercising judgement, discretion, and influence in matching community readiness with appropriate and responsive societal resources. As well, since Aboriginal people rely mainly on oral communication, ERs provide a service by packaging the people's views and plans into other forms of media. The staff and I frequently served as brokers between the grandmothers and institutions and other groups for securing support to enhance their well-being. Further, I routinely transcribed the grandmothers' formally and informally expressed opinions, ideas, and hopes into written communication for transmission to other groups, in that way conveying their input to external groups-- the health assessment report is the principal example.

Powerlessness in disadvantaged people "prevents them from organizing themselves or doing research,"[336] thus an external influence is often the catalyst. In our case, I was the ER and catalyst to nudge and guide the grandmothers into an inquiry of their own health. My roles were varied and changed according to what was needed and appropriate at the different stages of development in the project and research. These roles combined many general project functions and others specific to the research.

The literature includes a wide spectrum of thought on the appropriate role of the ER. Jackson[337] summarizes various authors' differing views:

- the principal responsibility of the ER is to the research process-- securing funding, supplying technical expertise, training local people in research skills; or
- the ER should take a more active pedagogical role; or

- the role of the ER, by rapidly conveying knowledge and skills to the community, converges and equalizes with that of the other participants; or
- the emphasis should be on provoking critical analysis by community participants of their reality.

Not necessarily by inclination or design, but determined by the nature of the grandmothers as participants, my involvement as ER focussed primarily on the research process. Because of the grandmothers' age, wisdom, life experiences, and learning style, I was neither comfortable taking a skills transfer role with them nor successful in eliciting a deep critical analysis of their reality; facilitating the research process was accomplished, however. Yet with the staff and research associates, I did play a pedagogical role with regard to PAR and health promotion.

Maguire identified triple roles of organizer, educator, and researcher in her participatory research. Whereas she found these multiple roles difficult to juggle, they served to ground me more broadly in the project and the lives of the grandmothers so that our differences were balanced by the many aspects of our lives that coalesced. In contrast to Maguire's, however, our work had the advantage of including initially the advisory committee to start the research design; then later the staff who became part of the research team and assumed some of the tasks involved, especially in organizing project activities in which the research was embedded; and then the research associates to assist the health assessment in various ways.

As identified in the descriptions of the project and research, roles I played included facilitator, researcher, organizer, educator, community developer, advocate (for the research, the project, various individuals, different issues and problems), friend, staff planner and administrative assistant, and project evaluator.

162

4.2.3 Personal Motives, Supports, and Benefits

Motives of ERs will differ, but making them explicit both to the other participants of the research and oneself increases trust and clarity in the relationships, purpose, and use of research findings. These motives, as well as assumptions, serve as guideposts for the direction and nature of the work as it progresses. As soon as I was given permission by staff to reveal my role in guiding the health assessment, I began to call myself the research facilitator and inform the grandmothers of my interest in studying PAR and health promotion as part of my academic program. Despite inserting this information whenever and wherever appropriate, so few of the grandmothers were familiar with graduate studies or grasped the abstract nature of my research that my presence and role in the project continued to be described as "the nurse." By the last year, however, many of the grandmothers were clear enough about my role to say that I was working on the research about their health.

To bolster my courage, faith, insight, and direction, other people beyond those already discussed became part of the informal PAR team and offered me much needed support. At times, I would consult with various members of my doctoral committee who had experience in PAR overall, more familiarity with Aboriginal people, or just good common sense about research and people, to steer me through "stuck" points. Some of these and others responded willingly and generously to form a "reflections committee" with whom I could meet occasionally to run through progress and challenges, or who read an early draft of findings and gave me valuable feedback. Other kindred spirits from family and friends joined this informal team. PAR is not a solitary pursuit; many minds and many hearts do make the path more clear.

Over the 2.5 years, I invested heavily of myself in the project and research, both personally and professionally, through the roles enumerated above, yet I gained back equally or more. The research experiment had many challenges and benefits, and was stimulating and enlightening. The field site afforded me the opportunity to return to practice after a number of years in academe. Continuing to work with

163

Aboriginal people, but a different subset this time, further increased my awareness of strengths and issues in their communities. Equally valued, the personal benefits of the experience for me were great, with close relationships built up among the grandmothers, staff, and me which were warm and satisfying. When I became ill near the end of the project, they were a source of caring and comfort to me. It enhanced our "power with" relationships further in that I, like most of the grandmothers, no longer enjoyed good health; we were wounded, yet supportive of each other.

Overall, besides effects on the grandmothers and staff, participating in the PAR experience had a profound effect on me,

- reclaiming my enjoyment of working in the field,
- restoring my faith in the wonder and worth of engaging directly with people,
- reinforcing my belief in the capacity of "ordinary people" to conduct research and affect change,
- strengthening my resolve to further incorporate my values and politics into my academic and work life, and
- feeling rejuvenated about being a woman and being with women.

4.2.4 Challenges

Challenges are inevitable and to be expected, and points of tensions that cause discomfort are many. Yet one must learn to accept these as part of the process of inquiry, learning, and change, while following one's instincts to work through them.[338] Griffin[339] proposed that these hurdles may be a gift of knowledge in disguised form, and they certainly do pose an opportunity for learning. My entire time guiding the research was spent with an underlying feeling of uncertainty, wondering whether our unconventional approach would materialize into a health assessment or not. I often felt as if I were holding my breath, hoping that things would fall into place, repeating my mantra, "Trust the process!"

From the point of initially proposing PAR to potential participants in the first thwarted initiative to the completion of this health assessment, I functioned with some trepidation. In both cases, I was the one, not the potential participants, proposing the research, asserting that there was a need for it, and insisting that research could be empowering rather than exploitative. I was making this argument as someone from the oppressors' population to people who were the oppressed. Not only were the grandmothers leery about research in general but they were being asked to be active co-researchers. With them, I felt I had to constantly rationalize, defend, justify, and persuade, which was a role I did not like. Furthermore, the coordinator and outreach worker felt uneasy in the early months of the project about broaching the topic of research and my role in it for fear of driving the grandmothers away from the project altogether. Their caution exacerbated my feelings of discomfort and added an element of deception to my relationship with the grandmothers. Since it was not the grandmothers who had identified a need to examine their own health picture, I would have preferred to work with them in an open-ended, community development way, encouraging them in personal and group growth and advocacy, and guiding them in inquiry and analysis as a natural part of their development. As it was, there was a pre-set agenda of doing a health assessment as one of the project goals, and of conducting PAR and examining its impact on participants within a certain time frame for my academic program. The spectre of failure loomed because of the importance of this work to the achievement of project goals and to the success of my doctoral program, and because of the skepticism of mainstream health research towards PAR.

Because I was an outsider and from the oppressor population, I endeavored to be inconspicuous enough to avoid dominating or shifting the focus off the grandmothers, or precipitating their silence. In my efforts to be unobtrusive and thus foster growth of the grandmothers, I consciously abrogated an active animator role, one which might have enhanced group development and critical analysis. Maguire,[340] too, writes of her reluctance to act like a trainer utilizing her full range of skills and techniques. She admits that this reluctance was a mistake: out of her fear of intimidating people, she lost opportunities to use

165

techniques to enhance participation. As with our grandmothers, few women in her research had experience or skill as group members, or in critical reflection and social action. I, too, did not use all my abilities in group facilitation yet pondered this possibility throughout the research. Did I decide correctly? For me, it remains unclear and inconclusive.

4.2.5 Lessons

During the life of the project and research and the exercise of writing this thesis, many lessons for the ER became apparent and are mentioned throughout this document. Key lessons are summarized here--the importance of relationships; the commitment of time and self; acceptance of uncertainty; and valuing the process.

Developing relationships of trust within the research team is fundamental, critical, and invaluable. As relationships among the grandmothers, staff, and me developed, the concept and language of health assessment research could be introduced, and acceptance cultivated for doing research together as one of the components of the project. There were a number of elements that fostered trusting relationships between the grandmothers and me:

- Home visits were the single most effective activity. I felt comfortable making these visits only after we had got to know one another in the group for several months. An aspect of these visits was to offer what Labonte[341] calls "respectful services"--meeting needs of the grandmothers that I was able to, such as inquiring about a medication, providing transportation to a funeral, or writing a letter;
- As women and mothers, we shared common joys and pains . Despite our differences, we could relate well to one another around various issues, such as our children's alcoholism and conflict with the law, and through our similar responses of caring and compassion;
- Genuine, sincere respect for one another grew, became recognized, appreciated, and articulated, and was accompanied by a growing affection for one another.

166

An ER must be prepared to commit time and self beyond what would be called for in most research. Time together, without the usual researcher detachment, creates comfort, builds trust, and fosters friendship. The grandmothers, staff, and I spent countless hours together, in each others' homes, project functions, committee meetings, and special celebrations. As Maguire says about her own relationship-building with the abused women participants: "There is no way to short-circuit the process,"[342] nor should there be.

As these relationships are built and project and research activities established, the ER lives with considerable uncertainty regarding the direction, nature, and extent of the evolving research which is only clarified as the process continues. I continuously played mental tapes to myself: "go with the flow," "hang loose," and "trust the process." The corollary to uncertainty is giving up control and giving it over, something conventional researchers or high-achieving professionals are not practised at doing; nevertheless, it is essential in PAR. The key decisions in PAR must be made and owned by the community participants, with the ER functioning as facilitator and a resource. To play that supportive role, I trained myself to be low key and a background organizer rather than take a front and centre role the way one learns to do in academic teaching and research settings.

Another critical lesson is to truly value the process at least as well as the product. This was brought home to me a year after the project finished and the health assessment report was published. On their own, the grandmothers organized themselves to put on a community workshop with the grant awarded shortly before the project closed. The health report was part of the registrants' packet and served as the printed resource for small group discussion during the workshop. The report was used more by the other participants than by the grandmothers. It was obvious that the grandmothers used their experience in the health assessment to develop clarity and confidence, enhancing their capacity to articulate their opinions and advocate for their own health. The process of doing the health assessment was instructive and empowering, and this was of more value to the grandmothers than the printed report.

This concludes my reflections on being an external researcher in PAR, reiterating that while each experience is indeed unique, there are some common principles, lessons, and processes that apply in general to using PAR.

4.3   Findings of Effects on Participants from Participation in the Health Promotion Project and Participatory Health Assessment

Since the central objective of this thesis was to examine effects of participation, the data were looked at, principally, for evidence of change in the project grandmothers who were the primary participants.   The reader is reminded that, with the agreement of my supervisor, this examination shifted to looking at effects of participation in the project as a whole, which included the participatory health assessment, recognizing that it would be unrealistic to ask the grandmothers to separate out their experience with the assessment from the overall project.

This subchapter presents the findings which pertain to that objective and are depicted as a model in Figure 3.   Participation in the project and health assessment research contributed to a number of changes in the grandmothers which I have categorized as: cleansing and healing; connecting with self; acquiring information and skills; connecting within the group; and external exposure and engagement.   These changes or outcomes are depicted on a circle to emphasize the interrelationships among them and to avoid an impression of linear development from one to another.   "Participation" was identified as the central determinant or influence on the outcomes, and "action" as a theme interwoven throughout.   Also shown are the major indirect contextual influences-- opportunity, encouragement, and mediation--of the social environment of the project, research, and community at large.   Beyond the findings portrayed in the model, the views of the staff on the project and research complete this data presentation.   The next subchapter, 4.4, discusses these findings and their relationship to PAR, health promotion, participation, and   empowerment.

This subchapter neither evaluates the project nor establishes cause-and-effect relationships between specific project activities and certain participant outcomes. Notwithstanding, some relationships are evident, for example, the grandmothers clearly attributed a personal therapeutic value to the healing circles. It could be argued, however, that other activities, such as individual support in the home, also contributed to healing, but in a more subtle way. Where grandmothers identified specific programming activities in relation to their responses, or where the staff and I saw a clear association, these are identified; where not, the cause is left to general project and research influence or to other unidentified variables. In my inquiries with the grandmothers, I did not try to isolate specific activities for the effects they described and, mostly, they did not identify discrete antecedents.

Quotations from the grandmothers are indicated in one of two ways: if short, they may be incorporated into the text using quotation marks; if longer or for special emphasis, they are set apart, indented, and typed in single space format without quotation marks. These quotations come principally from the set of taped individual project evaluation and participation interviews I conducted with the grandmothers, and from other sources of data that were hand recorded by the staff, research associates, and me. Intentionally, the use of quotations is extensive to ensure that the participating grandmothers have breadth and depth of voice. The italicized poetry is mine, reflecting my musings on what I "heard" in the grandmothers' words and actions, and what I imagined might be in their minds and thoughts but may have been left unsaid.

The data in these five categories are further broken down into subcategories:

Cleansing & healing

Self-healing
Self-care

Connecting with self

Self-understanding
Well-being, self-esteem, self-respect
Identification of own strengths and needs
Cultural and spiritual identity

Acquiring information and skills

Health education
Assertiveness
Articulation of strengths and needs
Learning about and gaining access to resources

Connecting within the group

Group identification
Mutual understanding and respect
Mutual learning and inspiration

External exposure and engagement

Willingness to influence the system
Reaching out
Speaking up
Community honouring

encouragement

participation

participation

cleansing
and healing

connecting
with self

participatic

external
exposure and
engagement

action

acquiring
information
and skills

connecting
within group

opportunity

mediation

participation

Figure 3   Areas of Change in the Grandmothers as Outcomes of
              Participation in the Project and Research

Over time with each other in the project, the grandmothers thrived as
individuals and as a group, and drew towards them the community at
large.   As one grandmother said of the others: they have "emerged out of
their shells."

Like blossoming flowers
turning to the sun
opening up their beauty
calling us to come

171

4.3.1 Cleansing and Healing

This section starts the categorization of data by painting a picture of the grandmothers as they evolved over the course of the project and our research, and is further divided into subcategories: self-healing and self-care. The project operated on the premise that we could organize programming with older Aboriginal women in our city that would play a role in improving their health. The grandmothers found healing value in their involvement in various activities and at certain times.

4.3.1.1 Self-healing

"After I left, I didn't have this ache in my heart."

For the grandmothers who were able to attend our healing circles, these clearly had a therapeutic effect. In an interview, one explained:

> Because it seems to me when I look at these older women, you can feel the love in that group which I think is very important and they are there to listen to you and you are there to listen to them. You have so much to share with one another in sorrow. But then again that sorrow turns into joy and you start laughing. Sometimes we'll be crying, but that's a part of the healing circle cause you're cleaning yourself. What's been inside you . . . so many months or years. And we have a chance to come right out and express ourselves, to clean everything out. Like the old people used to say, you're cleaning yourself because we have the sweetgrass. Before we had the healing circle and our blessing of the sweetgrass, which is very good at the start and then we pass around the stone, the sacred stone as we call it. That stone in there, something happens to you.

Another grandmother offered this explanation:

> . . . The healing circle helped me . . . Because I was having a problem with my daughter and I was feeling really hurt inside and it kind of helped to talk about it and realize that I wasn't alone in this world. . . And realizing that the other women understood, that they've been through it and all that and they offered encouragement. So to me it made me feel good inside, although there's nothing that I can do to change my daughter, but just the same, I guess really just the support from them made me feel a lot better. . . And I know the other

172

grandmothers too, the ones that have gone through it, have felt the same hurt that I did; the helplessness that you feel. So in a way that helped me because I think all these years I've always felt that I was alone and that I had to deal with them by myself and then I realized . . . and at one time I wouldn't have talked to anybody about any of my children doing drugs. But for some reason they made me feel comfortable enough to talk about it among a whole bunch of strangers. I was having problems sleeping. . . They shared their experiences with me . . . it made me feel a little easier . . . For some reason you just talked like it was the thing to do, you know. Afterwards . . . after I left, I didn't have this ache in my heart that I had when I went there that morning. It just kind of made it a little easier for me.

There was a therapeutic function to our healing circles. At one Tuesday morning get-together early in the third year of the project, most of the grandmothers present expressed how much they got from the group. One woman talked of being glad to be with the group again, after an absence, and that she had spoken the day before to the grandmother from the phoning committee who also has the same chronic disease, and they agreed how important it is to get out and stay active, like going to this group. Another grandmother spoke of her troubles with her adult children--one who died ten years ago from a fight, and another, now in his fifties, who was still drinking and had been thrown out by his wife and children recently and had then disappeared. She concluded with "Whew! It's good to get that out and off my chest" and said how she missed the group when she couldn't come last week and had asked another grandmother what we had covered, and that she was glad to be back this week, because this feels like a family, like we're all sisters. Another grandmother wept silently, then spoke of the difficult period she was having since the recent death of her husband, and how important it was to come here and laugh and talk with the others.

One of the house-bound grandmothers, during an interview, spoke about the value of the coordinator's home visits to her: "Since you've been coming to visit me, things have changed and worked for me a little bit better."

Typically, Aboriginal people seek out elders for guidance when troubled. Our project provided opportunities for the grandmothers to get guidance

from each other, too, both to talk out and resolve their own problems and to act as mentors and counsellors for each other.

4.3.1.2   Self-care

"I try to look after my health better."

All of the project grandmothers had contact with the mainstream health care system for treatment of disease for themselves and their families. Most of them had used what they called "Indian medicine" for a variety of ailments. Not many of them, however, thought that they involved themselves with the health care system to promote or enhance their own health.

The issue of self-care was complex and multifaceted. In many ways, the grandmothers were selfless, accepting that their primary role was to take care of spouses, children, and grandchildren, assuming that they had few rights of their own. They could agree that this selflessness was not fair, but they continued to function this way in their relationships with their families. Notwithstanding, they admired the exceptions to this rule and would hoot with delight to hear stories about women who broke this mold.

> You know --, my eighty-four year old auntie? She likes bingo and plays poker all night, and says to her children: *I brought you up healthy. Now I do what I enjoy, and don't tell me what to do.* Yet she looks after herself. She has so few wrinkles! And she looks absolutely outstanding!

In other ways, however, the grandmothers did take care of themselves. During our "present strengths" interviews, when we asked what they did for fun, the grandmothers listed a wide range of activities including bingo (often named with some hesitation and sheepishness), knitting, bead work, watching TV soap operas, community activities, family events, shopping, and more. They did not, however, think of these activities as health promoting, unless guided to reflect on them as such.

Since the central focus of the project and our research was the health and well-being of the grandmothers, their families, and their community,

174

we made self-care an active part of our regular discussions. One successful strategy was identifying and reinforcing activities and circumstances that supported health and those that detracted from it, thereby enabling the grandmothers to better understand what influenced their health. For example, many of the grandmothers were either diabetic themselves, cared for family members who were, or were at risk because of life style, obesity, and family history. Since sharing food was a part of most of our get-togethers, we used the opportunities to both discuss and use food that was suitable for diabetics, as well as weight loss, and controlling or preventing hypertension. Also, on many occasions we brought into our conversations the importance of balance, harmony, and other aspects of well-being. We stressed the critical interplay of the parts of the medicine wheel in contributing to health.

In the project evaluation and participation interviews, some of the grandmothers spoke about using their increasing knowledge of health for their own self-care.

> I try to look after my health better because I neglected myself.

> . . . since I've been hearing the information at the grandmothers' group, I've learned how to take care of myself more better and . . . I know what to do, and if I do need help I know who to turn to.

> And I find that, as a whole, [the project] has helped me in that [medicine wheel] circle again - mentally, spiritually, physically, and emotionally. Like my circle wasn't . . . I guess it's never perfect. Cause we always have to work on that circle, eh? And sometimes it gets kind of lopsided, some parts are missing.

On another occasion, one of the other grandmothers told me she had recently started weekly ceremonial circles and sweats with an elder in town, supplementing our project's monthly healing circle which she had been attending for two years.

For the grandmothers, taking care of themselves, considering personal health, and learning what and how to do this was a new experience. But we started talking about it as something worthy of doing, and we named it and gave it attention.

175

> *The grandmothers do --*
> *take care of others*
> *have no time for self.*
> *The grandmothers question --*
> *take care of me?*
> *do I deserve it?*
> *The grandmothers think --*
> *this is all new*
> *what do I do?*
> *The grandmothers ponder --*
> *never knew I could*
> *never knew I should*
> *The grandmothers think --*
> *time for me's fair,*
> *and yes, I care.*

4.3.2 Connecting with Self

The grandmothers were accustomed to putting others ahead of themselves. They were women, Aboriginal, and mostly poor. Their lives had been spent as caregivers, whether at home with nuclear and extended families and other community members, or at work outside the home in caretaking occupations. Aboriginal culture discourages drawing attention to the individual, and patriarchy gives little focus to women's needs. This produces a dilemma when personal needs are evident yet responding to these needs results in self-consciousness and discomfort because of its cultural stigma. The dominant culture has oppressed, dismissed, disparaged, and discriminated against Aboriginal people in general and, it could be argued, Aboriginal women even more so. The grandmothers, like other women, had to learn about themselves, their own strengths and needs, and how to alter circumstances for their greater fulfillment.

4.3.2.1 Self-understanding

"Going to the group has really helped me understand myself."

Different grandmothers often said how good it felt to meet with the group, talk about their difficulties, get things off their chest, feel the concern

176

and love of others, and realize that they were not the only one with problems.

> Going to the group, I guess you would say, helped me realize that it wasn't wrong to feel like that and . . . I think it helped me emotionally as well as mentally because I thought a lot about my mother and when she died, I had a lot of anger. And going there [to the project] helped me speak about this and I guess as I spoke about it, began to realize all to myself that it was only human to feel like that. And once I got this out of my system, my mind, it sort of like lifted a heaviness so that I started to feel . . . I'm not sure, happiness I guess you would say, you know, because I suppose of all the guilt I had felt . . . feeling I shouldn't feel like that to somebody who's dead. . . I think a great deal of going to the group has really helped me understand myself and my relationship with my mom.

On numerous occasions, both the health assessment interviews and the project evaluation and participation interviews were therapeutic. A primary purpose of the health assessment process was to acknowledge and affirm to the grandmothers their own resources. Those interviews, therefore, became an opportunity to mirror to them their traditions, strengths, and joys, as well as have them articulate and give vent to their concerns.

Our two research associates, after their first interviews, both remarked that the grandmothers they interviewed told them they enjoyed the experience. One grandmother said it made her think about the good times in the past which she had not done for a long while, and the other simply said the interview made her feel good.

When I was doing the project evaluation and participation interviews a year later, I wanted more grandmothers to volunteer to take part. At a Tuesday morning get-together, I asked the grandmothers already interviewed to tell the others how they had found the interview experience. The grandmother who spoke had come that day for the first time in a long time and was bright and talkative. She said: "It was good. It made you think of the changes in yourself [since joining the project]." Our individual time together in the interview, reflecting on the value of the project for her, had brought her back to the group that week.

> *So often alone*
> *with the burden of family*
> *running the same tapes*
> *of limited understanding*
> *and getting no where.*
> *Heavy heart*
> *sad life*
> *ache inside.*
> *What relief to talk*
> *to be heard*
> *to be understood*
> *to be affirmed.*
> *Gives a different look to it all.*
> *Is that how you manage it?*
> *Ah, I see.*
> *Ah, that's better.*

4.3.2.2   Well-being, Self-esteem, Self-respect

"I feel good now"

In our conversations and interviews, the grandmothers commented on feeling good. Often, they described a discernable improvement in how they felt on a day-to-day basis, attributing this change to the project. Good health was not something they readily achieved. They told many poignant, tragic stories of past and present hardships that influenced their quality of life. I felt humbled by a growing realization of the health strains and threats that each one of them lived with daily.

> There were thirteen of us children and we all survived childhood but not TB. Both my parents and all my siblings died from the disease. My mother was the first to die from it.

> I don't like being left alone. The TV isn't much comfort. There's no phone. I don't get any visitors. I can't get around very good.

Given the unique, stressful circumstances that each of the grandmothers came from and faced today, it is noteworthy that participation in the project could contribute to a sense of improved well-being.

The grandmothers indicated in a number of different ways--in interviews and conversations, and through their actions and behaviour-- their growing self-confidence, improved self-concept and self-esteem, pride in themselves, improved deportment, and personal health.

> I feel good now. It seems like my health . . . [has] improved, because that helps you when you go out and you're among . . . older women. You forget about . . . yourself. It's just like it's a new me, a new person. That's the way I feel. It's just helped me a lot, you know . . .

> . . . when I was working, I was always involved with different things and a lot of people, all the time. But when I quit working, I said I was not going to be involved in anything for a whole year. I didn't want to attend any meetings, anything, for a whole year and I think I did that. And then during that time, I noticed that, coming into a new place, [this city], I was starting to withdraw, and I was losing touch of everything. Losing touch of the world, I'll say. And also I've noticed that, should I say, I was getting edgy, maybe, too . . . Since I've joined [the project], it has [brought] me up, my whole self. It has sort of nurtured my feelings. I feel happier and I made friends.

As well as commenting on changes they saw in themselves, the grandmothers described what they saw in the other participating grandmothers.

> Oh yes, I have [noticed changes in the others] . . . They're more open. They're more relaxed. They're ready to share whatever's bothering them inside. They're friendlier. . . . You can see and you can hear them, they are really feeling good, because I guess they have shared, and [you] know that someone is feeling for you.

> . . . when they first come, they had weaknesses in themselves. Like for myself, too, but now about the middle of the project, I've noticed a strength was coming in them.

Feeling good carries over to looking good. Half-way through the project, I remarked to one of our most regular grandmothers how nice she always looked now. The last few times I had seen her, her hair looked nicely done and her clothes were matched and attractive. At my comment, she replied, with a chuckle: "And I'm not going to dye my hair anymore!"

In their homes, most of the grandmothers continued to take care of others--grandchildren, a debilitated spouse or adult child, troubled adult children--often as their own health deteriorated. In the project, the

179

grandmothers themselves were taken care of--rides provided, food shared, respect given, advice requested, and worth affirmed. They were given much attention by others and, in turn, they gave this to each other. This caring helped them feel better about themselves.

> [The grandmothers'] sense of humor . . . I believe that has helped, you know. That has helped because I can tell you . . . before I went to the group, [my husband] couldn't joke with me. No. And he's the kind of person [who] jokes. He couldn't joke with me because I would get mad at him and it was getting to the point where I would . . . like every other word was f--- or something like that and I was not a person to swear like that. So going to the group has sort of, not mellowed me, but sort of made me . . . brought a calmness about me, my life.

<p align="center"><u>"I feel good now"</u></p>

<p align="center">It doesn't take much
a little attention and caring,
kind words, warm clasp.
That was enough for
reserve to drop,
a face to open,
a smile to break.
A glow spreads on one to all.</p>

4.3.2.3 Identification of Strengths and Needs

Early in the health assessment, the grandmothers let me know they did not want to dwell on their problems. In response, I suggested a shift to looking at their strengths. They agreed but had difficulty identifying and expressing strengths. After several weeks of work preparing for the health district's Aboriginal consultations, focussing on what the grandmothers embodied and could contribute to a partnership with the health district, one of the grandmothers turned to me and asked, "Now, just what are our strengths?" Despite identifying traits and values important to holism in the health care system, they continued to have difficulty seeing these in themselves in relation to institutions beyond their immediate families.

They were silent not only on their strengths but also on their needs. Yet in the safety, support, and opportunity of the healing circles, they

gradually disclosed their wounds, concerns, and pain. With their permission, I used these healing circle stories and responses from the group interview on problems to compile two of the sections of the health assessment: "disruptions" and "concerns." By the time we put the assessment model and report together, and following consultations with the health district and social services minister in which they voiced their concerns, they were more comfortable with openly discussing their problems. Also, through the slow, participatory process of the health assessment, in tandem with trusting relationships being built among us, they began to articulate their strengths. One of the first strengths to be named was the support they gave each other for their pain.

> It's a good feeling that when we're talking in that healing circle, the ones sitting around are listening to you and they're feeling for you, and they care for you and that's part of the healing. And that gives you more strength. That's one of the strengths.

4.3.2.4   Cultural and spiritual identity

"I have now genuine pride in my Indian ancestry."

As I found in my other contacts and work with Aboriginal people, only some are familiar with their traditional culture. Most grew up in an environment more shaped by the Christian churches and government policy than their own beliefs. In fact, the churches and governments actively worked to eliminate Aboriginal culture and achieve assimilation. This resulted in most things indigenous and traditional being depicted as barbaric and pagan, and youngsters, particularly, grew up learning little about their own culture and being ashamed of remaining practices and beliefs.

Too commonly, the contemporary lived experience of many Aboriginal people shows little relationship to the harmonious, respectful, proud, wise aspects of their ancestors' lives. Sadly, today's experience is more shaped by negative influences: being marginalized and discriminated against in the dominant society, feeling alienation toward mainstream and urban culture, finding little relevancy in or aptitude for mainstream education,

181

struggling with chronic poverty and limited employment prospects, being subjugated by a welfare existence, and being influenced by dysfunctional behaviours and relationships.

In the project, we saw results of those negative influences in some of the grandmothers to varying degrees: distrust and refusal to participate in certain traditional ceremonies because of Christian teachings; histories of abuse and addictions in themselves and their families; current environments threatened by abuse and addictions; grinding struggles with poverty; lifelong feelings of low self-worth; and poor health due to lives of physical and emotional hardships. Despite this legacy, across Canada Aboriginal people are gaining both their own momentum and public support for greater self-determination, cultural protection, and a fairer proportion of what this land, their historic land, has to offer.

A number of comments in the interviews and other data sources referred to the grandmothers' growing knowledge about and pride in their Aboriginal culture as a result of their participation in the project. When asked about changes she has seen in herself since being involved in the project, one grandmother replied:

> I'm more aware of Native spirituality. After years of being taught
> that my people were savages, I have now genuine pride in my
> Indian ancestry . . . Although I've always respected them, I have
> more insight into spirituality and I can sincerely take part in the
> healing sessions and certain rituals. For instance, the sweetgrass
> after it was so beautifully explained by [the elder] where after
> cleansing our mind, our souls, our hearts, we're better able to . . .
> come before God, present ourselves in prayer. I thought that was
> really a beautiful idea. I don't see anything pagan about it, but some
> people still think it is. I now have a genuine pride in my ancestors,
> whereas it used to be only there, like just below the surface. After
> all that negative teaching, I always held my head up and never
> denied my ancestry. But now I hold my head much higher and I'm
> genuinely proud to be an Indian.

Another emphasized that grandmothers serve as cultural role models for the young.

> We feel, as grandmas, . . . we're placing ourselves and looking at
> ourselves as a role model for the young kids of today. We're also
> educators, to educate other people so that they don't forget who they

182

are . . . [when] they hear us talking about ourselves, about childhood. And another thing too . . . our culture is based on freedom and harmony among our people . . . I think this is why they formed our project, a program based on older Native women. . . Because we have a chance to say what we wanted to say from our own hearts so that some day . . . the kids, the children, know. . . that we're not going to be here forever, but then again [they] know . . . that we're going to leave [our culture]   behind that's very precious to everyone.

There were a number of comments in the interviews by the grandmothers regarding learning Aboriginal culture through their participation in the project.

I like meeting with the ladies . . . I've gotten some information that I could use and I like to learn, especially about Native subjects and I feel that some of the other ladies know a lot about culture . . .

Two of the Metis grandmothers talked about the different traditions and ceremonies of the First Nations (treaty) women:

You have a chance to meet other women, but most of these women are all Treaties and I never seen the way their culture is. The healing and the tradition I never knew. That is the first time I ever seen that--the healing [circle] . . . I'm curious of the way of Treaties off the reserve. . . It's really interesting sometimes the way . . . none of them is ever had any amount of anything, but they had themselves . . . They really got it all together and they loved each other.

I like to go there [to the group] and even just to talk and to listen and always learn a little thing there that I didn't know about because, you know, I've never lived on the reserve and just to listen to them talk about things. I like to listen and you learn lots of different things. . . I like observing what [treaty women] say about their life and listening to them talking about what they do, like the healing circle and that. I don't understand that at all. To me, I don't understand because I never was in one. I don't know anything about this sweetgrass. I don't even know anything about that. I've never even seen that in my life . . . So I'm learning a lot of things that I didn't know about, through the project, with them, learning their way of life.

Another way the grandmothers showed their growing interest and pride in their traditions was their enthusiasm for meeting, at any opportunity, with elders** whom they respected for their unique calling and wealth of knowledge. For example, at one of our Tuesday morning get-togethers,

five grandmothers quickly indicated interest in meeting with elders to discuss health-related questions as part of the health district's Aboriginal subcommittee's community consultations. During the subsequent half-day spent together, the grandmothers both listened and contributed to the discussions on traditional perspectives on health.

After reading a draft of the health assessment report, one of the grandmothers commented on a heightened awareness of her culture. She had not personally known of many of the beliefs or experienced many of the practices that others contributed to the report.

> It really helped me to read this, 'cause I may have said one thing, but others have added more and I understand better now. And I asked [my husband] about it and he said, Yes, it was like that. And he was taught by [an elder]. I really loved this [health assessment report] because I didn't go through this myself.

Despite distinct cultural and socialization differences among the grandmothers, varying degrees of traditional knowledge and practise, and further assimilation into dominant society urban life, the grandmothers all thought of themselves as Native or Aboriginal. At every opportunity, the project emphasized both their uniqueness and their common Aboriginal ancestry. This philosophy enabled scattered individuals to see themselves as a community with common, identifiable characteristics and practices of which they could be proud.

I have now genuine pride in my Indian ancestry

Head held low
eyes downcast
pagan ways
from our past.

No, that's wrong.

Head held high
eyes ablaze
proud traditions
cultured ways.

4.3.3 Acquiring Information and Skills

There was great heterogeneity among the grandmothers. A few were bicultural, moving easily between the Aboriginal and White worlds, possessing information and skills to support them in both, including the traditional and western health care systems. Most were more comfortable in the Aboriginal world and fewer in the White world. What information and skills they gained from the project and our research depended on their starting point, their motivation, and the degree of their participation. Learning was continuous, usually informal except for the educationals, and ranged from personal attributes like assertiveness to how to secure institutional resources.

4.3.3.1 Health Education

"We have learned a lot."

In the educationals, the grandmothers were typically a polite, uncritical audience. Their level of participation depended both on the style of the guest and the particular composition of grandmothers at any one session. When a session was not well received by them, the usual reason given after the guest's departure was that the language was "too high." The grandmothers were annoyed when the vocabulary and style of speaking of the guest was too complex for their easy understanding. They clearly felt marginalized and that topic was given less credence.

In the project evaluation and participation interviews, I asked the question: What are the best things about the project? A few of the grandmothers mentioned the educationals; some of their comments were:

> I've come to learn how to deal with my diseases that I have . . .
> hearing it from other resources that have come to speak with . . .
> our group. That helped an awful lot because we have a chance to ask
> questions, because that's what we're there for, to ask, to learn and
> you learn a lot from your own mistakes and your past . . . I'm
> learning about the diseases . . .

> When we have those little workshops, those educationals on diabetes,
> high blood pressure, menopause, . . . it refreshes you. . . . No matter

185

how old you are and no matter how much you have learned in the past, we have learned a lot [in the educationals]. And even things that you knew before, it refreshed your mind. It has helped me a lot, like that.

For those who were interested and for whom the topic was relevant, the educationals had some benefit. Most of the grandmothers understood little about the Western medicine perspective of the illnesses and conditions that afflicted them and their families. Some wanted to better understand them. At other times, though, there were a few who were reluctant to deal with their own situations for fear of learning something negative. One grandmother said: "I'm afraid to go to my doctor in case there's bad news, or more surgery's needed."

For many, the educational was a social occasion. For others, it was instructive--specific questions answered, concerns discussed, new information learned, and changes made at home.

"We have learned a lot"

We feel like hosts
graciously inviting
guests to join us.
Listen politely
offer tea
nod our heads.
For some
hear new facts
ask the questions.
For others
enjoy the occasion
sip our tea, go on home.

4.3.3.2 Assertiveness

"I've become assertive."

In various ways, the grandmothers showed their growing self-confidence and improved self-esteem through demonstrations of assertiveness and advocacy.

186

The first time I met with the grandmothers was in February, 1993, in my assigned role as nurse educator for a Tuesday morning get-together. This was only the second time they had come together as a group. We were to discuss diabetes, the topic requested by the grandmothers. The setting was a basement meeting room, dimly lit, in the neighborhood social services building. Thirteen grandmothers attended, all sitting quietly in chairs arranged in a circle. The morning was opened by the coordinator with sweet grass smudging and a prayer, followed by announcements, and then the educational on diabetes which I was to do. Even though I tried to encourage dialogue, only three grandmothers spoke up with comments or questions. The others were silent, often with eyes downcast--a sign of respect and shyness.

Over the next year, the grandmothers who came regularly began to relax and be comfortable with each other, the staff, and me, and they started to participate in the discussions. Even with the normal range of personalities, the grandmothers were quiet and reserved but with a good sense of humour. A few of them would tease and tell jokes and suggestive stories, which would break the sobriety of the group and have us all laughing uproariously. On more than one occasion, staff from adjacent offices said we were having so much fun they wished they could join us.

This was the side of the grandmothers I usually saw: shy, gentle, enjoying a good laugh. I took note and was impressed, therefore, whenever one of them spoke up for herself or others, or on an issue. I reminded myself, however, that their quiet demeanors masked characters of strength, developed from years of confronting adversity. These women had spent much of their lives facing numerous formidable obstacles--racism, sexism, poverty, classism, violence, addictions, neocolonialism, and isolation. Yet they were with us in this project, showing spirit, humour, and enough health and well-being to be involved. One of our most quiet but regular grandmothers said to me firmly: "I don't have no trouble saying nothing to nobody."

Yet this was often not the case with close family, although most grandmothers reported making progress in asserting themselves at

187

home. During our "present strengths" interviews, we asked the grandmothers if they ever said "no." Most said they have learned to do so, but it hurts, especially with their children and grandchildren. One said it hurts because her father never said no to anyone and he was a community leader. Another said "it hits [sic] your feelings [to say no], yet in the head you know you're doing the right thing."

For most, if not all, of the grandmothers, their resilient approach to life came from a lifelong struggle to survive and protect themselves and their families. In the project, this resilience expanded to encompass advocating for themselves in matters beyond their basic needs and advocating for others beyond their immediate family. The project fostered this through our relationships and activities with each other and community partners. Examples of this new assertiveness were seen in the way they felt about themselves, behaved within the group, and interacted with others.

In the individual interviews, two of them spoke of changes at a personal level.

> I used to fly off. . . I control my temper now. I've learned to control myself. . . I'm more sensitive and caring. I cared for my most immediate family. I care for other people now - like [one of the other grandmothers], losing her daughter.

> And I can tolerate things more and I can say that I've become assertive. . . I feel good about that. And it has built up an awareness, too, within our circle within the project, knowing that really you are not forgotten, that you are an important person, and you feel good inside.

Shyness was a characteristic that came up repeatedly in the interviews when I asked the grandmothers to comment on changes in themselves and the other participating grandmothers seen over time with the project.

> Before I took part in the project, I was very shy and unable to speak for myself. I was uptight about everything, .. . tongue-tied. It seems like something was holding me back from saying anything. Now I'm able to speak out for myself.

Often, the grandmothers were better able to describe changes in others than they were in themselves.

> . . . They [the other grandmothers] came in very quiet, very dull looking and . . . [now] they seem to be more alive, not so scared of everything . . . They can speak out more for themselves than when we first started out . . . They're not so scared that something will happen to them . . . They get more relaxed . . . They're not so shy . . .

The grandmothers also demonstrated assertiveness within our project group by working on clarity and effectiveness of roles, tasks, and communication. One of the grandmothers told me that she straightened out a sensitive disagreement between a staff member and herself by calling her to come by and having a frank discussion about it. Another sensitive situation involved one of the grandmothers' nieces who worked for the project for a few months, but had not turned in much of her work or her office key on termination, despite several requests to do so. The grandmother, one of our very shy ones, concerned about her niece's lack of accountability, offered to intervene and talk to her about this unfinished business.

For a period of several months, we videotaped our get-togethers and meetings so that we could capture material for our health assessment and other possible uses. On the Tuesday morning that we started, one of our grandmothers rose to the occasion by leading the group in a discussion of traditional values. Her demonstration of ease relieved the awkwardness others were feeling in having a camera in our midst, and increased the comfort level.

Assertiveness was also demonstrated by the grandmothers vis-à-vis other individuals and institutions.

> [When] my daughter . . .. was so upset [about racism at her elementary school]...I phoned [our project coordinator]. I wanted to confront the parents and [the coordinator] said, "Don't do that." She said to phone [Police Sgt] H. He was helpful and sent a man over within a half an hour. If H. hadn't come to our group [to speak to us about community policing], I wouldn't have known what to do . . . I would have done it the Indian way and banged heads!

189

There were numerous examples with the health care system in which different grandmothers demonstrated their ability to advocate for themselves, sometimes with some support from the project. One situation concerned a grandmother who had a chronic post-operative wound infection, following abdominal surgery. After months of problems, a second surgeon found surgical material left in the site at the time of the operation. With the wound finally resolving, the grandmother and I composed and sent a letter to the provincial college of physicians and surgeons reporting her treatment.

The grandmothers also asserted themselves as a group, doing what they saw was best for themselves. The provincial health council was conducting community consultations for its community goal-setting process. The council offered to send a facilitator to meet with the grandmothers but set a very tight time line. Our project was in the middle of planning a feast and the grandmothers decided they should not be burdened by someone else's schedule, even if they did want to have input to the goal-setting. One of the grandmothers spoke for the group: "No, we'll just not be able to meet their schedule. We'll get our comments in when we can."

Quiet, composed, strong women further built on their strengths, for themselves, in new ways and new dimensions, and for others beyond their immediate circle.

"I've become assertive"

Shy retiring violets
with stems of steel,
resilient
against the elements.
Bunch together
strength in numbers,
reach
and grow together.

4.3.3.3 Articulation of Strengths and Needs

Over much time and with much effort, in bits and pieces, the grandmothers identified the strengths and needs of themselves, their families, and their communities. Then, they both sought and took advantage of opportunities to articulate these to others. Yet even after working repeatedly on the overview of their health in the form of the health assessment report, when the grandmothers spoke to others they usually talked either of their own personal circumstances or about the plight of their grandchildren. With guidance and technical assistance they could paint the big picture, but more naturally spoke about the immediate and personal.

Many of the grandmothers had never attended a formal meeting before and most had never spoken in public. Despite this, a number became regular participants on coalition committees and frequent attenders at public events, and they learned to contribute their opinions. For example, most of the grandmothers received benefits of some kind through government sources: disability, income assistance, old age security and income supplement, retirement and employment pension. Those benefits received through social services, either for themselves or other family members, often seemed to be contentious in some way. The grandmothers complained of not being clear on policies, disagreeing with classifications and allocations, not getting through to their workers when needed, or feeling their treatment was discourteous. They decided they would like to speak directly with the provincial social services minister.

When the minister accepted our invitation and set a date, we prepared for several weeks by discussing issues to present to him, and we met the week prior to his session with his local Aboriginal supervisor. Then, the morning he came to the project, the grandmothers spoke clearly, confidently, reasonably, and politely, explaining their issues of concern. The minister later wrote a letter to the grandmothers to express his appreciation of their discussion with him. Also, he told his senior community development officer how impressed he was with the

191

grandmothers, that they expressed well the concerns of Aboriginal people in general and those on assistance, and that he would like to meet with them again. As I drove grandmothers home after the meeting with the minister, they chatted about how well the session had gone, how he took notes of their concerns, and how good it was to be heard. I commended them on their comments because they had spoken frankly yet cordially, representing both their hospitality and concerns so well. Perhaps because of their age, life experiences, or relative unsophistication, the grandmothers had a direct yet courteous manner that was clear and refreshing.

Two weeks later, the Aboriginal subcommittee of the health district board was on the agenda of the board's regular meeting to present the recommendations we had formed from the first consultation with Aboriginal people held earlier. Four of the grandmothers and I accompanied the subcommittee chairperson (who was one of our former project advisory committee members). One of the questions posed to us by the board was about our desire to do a community needs assessment since Aboriginal people complain about being researched so much. Our chairperson said that we would do it differently--holistically, giving attention to spiritual and emotional health and focusing on strengths, naming the grandmothers' experience in our health assessment research as a model. On the trip home, we all felt excited and encouraged by the opportunity to speak directly to the board and the positive response we got. One of the grandmothers remarked: "I didn't think we'd get anywhere with this, but I feel we are!"

The grandmothers clearly felt empowered in initiatives like this. However, their increasing capacities to identify and articulate needed change were always tempered by systemic, socioeconomic barriers to good health which were more resistant to change than they themselves were.

4.3.3.4   Learning   about   and   gaining   access   to   resources

"How   many   know   there's   a   VON?"

The poor health experienced by many Aboriginal people in Canada can be attributed to many factors, notably socioeconomic disparities and cultural disruption. Additionally, for those in the city, health is affected by problems of adaptation to urban life, unfamiliarity with urban health care systems, and Aboriginal/non-Aboriginal communication problems which exacerbate preexisting health problems.[343]

Our grandmothers' experiences with the health care system were far ranging, from much satisfaction on the part of one grandmother with her doctor and surgery, all the way along the spectrum to others' great dissatisfaction with the system's cultural alienation, impersonality, and its focus on physical illness only, given the Aboriginal perspective on holism. The grandmothers often shared vignettes about their lives, including contacts with the health care system. They expressed confusion about illnesses described, tests ordered, drugs prescribed, or advice given. As well, they were not well enough informed about services and supports available or how to gain access to them when needed. The staff and I often worked to identify appropriate resources within the health care system or elsewhere to better meet those needs, pointing out their existence, and emphasizing the grandmothers' right and way to gain access to them.

One grandmother, for example, looked after a debilitated, diabetic husband. She was concerned about the deteriorating state of his feet. Together, we found out that the Victorian Order of Nurses (VON) offered a foot care service in the home, and that the Department of Indian Affairs covered the cost in some cases. We met with the VON director who processed the paper work and got the service started. The grandmother carried out the arrangements from then on. She shared her experience with the other grandmothers: "Another thing, too, we did in the [project], the good thing, we got help with, for example the VON. How many know there's the VON?"

193

Another example involved our coordinator who realized that some of our grandmothers with serious illnesses did not have telephones and might be unable to contact anyone in an emergency. She inquired of the telephone company and found that there is a service for medical need in which a down payment is waived and long distance calls can be blocked to prevent charges being accumulated through others' use of the phone. Four of the grandmothers got the necessary medical authorization from their doctors, worked with the coordinator to process the paper work, and got their telephones set up.

After identifying a resource, the staff and I tried to work with the grandmother on the first contacts but then handed over the follow-up to her so that she was in charge of seeing the service through. I always encouraged the grandmothers to share their stories with the others as examples of getting their needs met through the health care system. These experiences showed that help could be got with persistence, that they had a right to a broad range of resources, and that they could help each other learn how to gain access to them.

The grandmothers began to see that the health care system was composed of more than doctors and hospitals, that other institutions could be accessible to them, and that they could exert influence so the system worked for them.

"How many know there's a VON?"

How am I to know
what's in there?
It's all White.
It's all strange.
It's supposed to help
when I'm sick
but it doesn't.
Let's find out
what's in there.
It's there to help
when I'm sick.
It should.

4.3.4 Connecting Within the Group

The next clustering of data pertains to connections that the grandmothers made with one another within the group. The subcategories are: group identification; mutual understanding and respect; and mutual learning and inspiration.

Over time in the project, the grandmothers developed an increasing sense of group identity. For example, the greetings they gave one another became warmer and more demonstrative, they introduced themselves more easily to others as being part of the project, and they initiated contacts among themselves on their own and more frequently.

Yet the expectations the staff and I held about the group were unrealistic. At a year and a half into the project, the staff and I discussed and challenged ourselves on our expectations of project accomplishments and the grandmothers' involvements. We concluded that we were too ambitious, and reminded ourselves that the group-building phase of community development and PAR was essential and critical, time-consuming, and could not be truncated or minimized. Thus we had to adapt our programming to this realization.

Group-building and attention to group identity are particularly important with Aboriginal people who value, in ascending order, the needs and well-being of the individual, the family, and the community. On many occasions, different grandmothers said to me that they did not like being singled out or speaking as an individual; that would be bringing inappropriate attention and importance to oneself. The grandmothers were much more comfortable functioning as a group when participating on committees and in events, giving their opinions, and being identified as Aboriginal grandmothers.

4.3.4.1   Group   Identification

"We're   just   one   happy   family."

Most of the grandmothers had moved to the city from small communities in their later years to be close to their families and medical services. They usually lived with their children or the children lived with them. Often, the grandmothers took care of grandchildren and other dependents, and had few other contacts; they were isolated. Some were unfamiliar with the city, or lacked transportation and friends in town. If their family was troubled, so were they.

When they became involved in project activities, the grandmothers found companionship, fun, stimulation, and closeness.

> I've been able to make more friends with my own people and the staff involved in the project.

> . . . It seems like we're just one happy family. . . . before . . . I didn't get involved as much after my retirement. I sort of stayed in the shell for a while, kind of hideaway. I don't know why I did that. After I had my cancer, I just felt that everything collapses on you when you have that, so I just walked away from everything. But since I'm back, I'm back in the picture--and I'm talking about . . . coming back into this project. I know there's hope, reality, pride and dignity in the project for the grandmothers . . .

With the grandmothers who did not come out to our group functions, the staff made home visits, sometimes taking other grandmothers with them to make the shut-in grandmother feel part of the group.

> Before I knew you, there was nothing, nobody around. Now, since you've been coming, I always expect someone to come visiting.

The grandmothers began to act, gradually, like a close-knit community, which is something most of them had grown up with, either on a reserve or in a rural area. Being part of the family of grandmothers allowed them "to be old ladies" rather than burdened caregivers.

In the city
strange and cold
where do I go
whom do I hold?
Ah, the kohkoms
the grannies
my new friends
the old ladies.
Speak my language
laugh with glee
eat the bannock
drink some tea.

4.3.4.2   Mutual Understanding and Respect

"We have so much to share with one another."

Most community people in contact with the grandmothers had an intrinsic sense of their worth, and a respect and admiration for their wisdom, experience, and love.   But the grandmothers took time to develop that about themselves.   Nonetheless, through continued contact with one another, their appreciation of themselves increased.   There was an interplay between the rising esteem a grandmother developed for herself and for the others.   The former was the slower half of the equation to change, however, and their low self-worth could be traced to their youth.

> I grew up Metis among richer French farmers and never learned to fight back.   I was left with bitterness and an inferiority complex.   It never really leaves you.

There were many expressions of admiration by the grandmothers for each other.   Two years into our project, the health district's Aboriginal subcommittee organized a series of consultations involving various community groups in a discussion about key health questions.   At the one for elders that our grandmothers participated in, I presented the framework and excerpts of content from our grandmothers' draft health assessment, as an overview of the health discussions our project had already held.   At the end of the consultation, on the way home, one of our

197

grandmothers commented on quotations from the grandmothers I had read out, which included some from herself:

> They're really something, aren't they? What you said those grannies said. Who would have thought they could talk that way!

One of the principal aims of our project was to foster the development of a community of grandmothers. Those participating in the project spoke readily about what they gained through project activities, especially from one another.

> It's so peaceful just to get the women together for a meaningful conversation. Just being part of a group is worthwhile at our age.

During the project evaluation and participation interviews, I asked the grandmothers what they liked most about the project. Almost all named the healing circle because of the caring they experienced in the group and the value of sharing parts of their lives with one another.

> . . . before I felt kind of lost with no one to talk to and no one to share my problems with. But at the group now, I can openly talk about anything.

> . . . there's tears and there's laughter. We share that, there's a lot of sharing, but also there's a lot of love there and caring and it's improving. I can see that, as I say, you feel that people are not as tensed and I guess, on the whole, it's the whole support system.

The grandmothers connected with one another in various ways. For example, each Mother's Day, one of the grandmothers went down the project phone list and called everyone to wish her Happy Mother's Day. Several of the grandmothers telephoned each other regularly on their own, and kept in touch in between our get-togethers.

They also formed special bonds between them:

> We often go through the same things and we always turn to each other. We phone each other when we need a shoulder to cry on. And I notice like when she talks to me about something that's happened to her and it's a similar thing that's happened to me and we can talk it out, help each other. And I feel good about that.

198

Another frequent theme was the realization that a grandmother was not alone in the problems she experienced; others had similar struggles.

> . . . from listening to some of the other grandmothers . . . about their problems . . . tells me that I'm not alone. I'm not the only one that has the same problem. By listening to them I know how to help myself.

Despite their individual struggles with self-esteem and self-confidence, the grandmothers respected and admired each other for having the role and wisdom that older women traditionally had in their Aboriginal society, and they valued sharing this respect and admiration among them.

"We have so much to share with one another"

> *Before I was alone*
> *now we have each other.*
> *I talk they talk*
> *we smile at one another.*
> *They're my sisters*
> *we love and care.*
> *It feels so good*
> *we laugh, we share.*

4.3.4.3   Mutual   Learning   and   Inspiration

"I learned a lot from them as well."

The grandmothers were their own best role models and teachers. They learned from one another by listening to each others' stories, opinions, and advice, and by seeing the others as good examples of being women, grandmothers, and Aboriginal people.

During the interviews, there was frequent mention of learning from one another.

> Yeah, I've noticed that I've been able to talk about a lot of the problems that I've encountered so far like with my health and with a lot of stress that I've been under . . . from listening to some of the other grandmothers . . . about some of their problems . . . It helps me deal with some of mine.

What they learned from each other extended from the mundane to the profound.

> I exchange ideas with the other ladies, [for example,] they say, 'Put your feet in warm water, rub your feet.' The older ones say that.

> I think I would say I'd become more happier [since becoming involved in the project] . . . What . . . has also helped me . . . is something that [one of the grandmothers] had told me when I told her that I feel the loss because I don't have anything to pass onto my girls, like my knowledge of my culture. Like not even the language and that, I can't even pass them. I said that and she made me feel that it wasn't my fault . . . So I've gotten . . . a lot of support from [the grandmothers] . . .

The maximum age difference of the grandmothers who participated regularly in the project was about thirty years, from forty years of age to seventy. In traditional Aboriginal fashion, the younger women looked up to and listened to the older ones, took their advice seriously, and saw them as role models. Even a modest increase in age implied greater wisdom and earned automatic respect. A sixty-two year old grandmother commented:

> You know these older women, they have such words of wisdom. And so much encouragement you get from them and that just strengthens you, you know. I don't think I could ever get that elsewhere . . .

> . . . but [the older grandmothers] have a lot more experience. They have a lot more knowledge than the younger grandmothers do. They've experienced a lot more.

The younger grandmothers were heartened to see the older ones enjoying life as they did when they came together in the group.

> And I think as far as growing old and all that stuff, I look at these other old ladies and I think "Ah, maybe it's not so bad" because I got frightened when I thought about it. . . They have a lot of jokes that they laugh about. You know they can laugh at themselves . . . It's nice to see somebody being able to [do this] . . . I've seen a lot of grouchy old people in my life time, but they certainly are not one of them. They enjoy life.

One of the contradictions of the grandmothers was that they naturally looked to one another as sources of wisdom and knowledge yet the individual grandmother felt very uncomfortable if singled out as this

source. I concluded that their mutual learning was done most effectively at certain times: getting together informally, sharing daily experiences and lots of laughs, and admiring each others' spirit and outlook on life; talking in circle format, either as a healing circle or a discussion about a topical issue or decision to be made, so that each had her chance to relate a personal story and opinion; and speaking to one another privately, often after a healing circle, to affirm a reality described and allay oft-expressed guilt and responsibility especially about anxieties over family matters.

The obvious affection, admiration, and respect they held for one another went a long way to strengthening their own self-worth and sense that they were fulfilling the traditional role of older women.

> I'm just proud to be a grandma and be able to share my grievances sometimes, my sorrows and be with the other women and then knowing that they're there to listen and they care. You can see that in their faces when I used to talk to them and they listen and help me, especially going through all this ordeal with my son and the accident. The grandmothers gave me the strength. I got all the strength from them because I know they were there for me and I learned a lot from them as well.

<div align="center">

"I learned a lot from them as well"

This is where we find the knowledge
in the hearts and minds
of these older ladies.
This is where we learn our ways
in the words and strength
of these older ladies.
This is where we see our culture
in the thoughts and prayers
of these older ladies.

</div>

4.3.5 External Exposure and Engagement

This last clustering of data showed outcomes involving the grandmothers of the project with others external to the project and on issues that might not immediately affect them. The data revealed several themes and many examples of the grandmothers reaching out and establishing external community connections, relationships, and partnerships; learning more

<div align="center">201</div>

about and critically analyzing community issues important to them; becoming activists, speaking out on issues and being involved in decision-making; and being recognized and honoured by the community at large for their intrinsic value and their special contributions. The subcategories are: willingness to influence the system, reaching out, speaking up, and community honouring.

For many of the grandmothers, involvement in any sphere beyond their families was a new experience. Most had now become comfortable participating at the project level but forming working relationships with other committees and agencies demanded a new set of skills and self-confidence. Halfway through the project, for example, at an initial meeting of the health district's Aboriginal subcommittee, the chairperson asked everyone to declare his or her willingness to ongoing participation on the committee. One of our grandmothers was silent. Later, our attending staff coordinator asked her about her interest in continuing. She replied that she had never before been a part of a group or learned to say things in public but was now learning to speak up a little, was enjoying it, feeling better about it, and, yes, would continue.

Over time, the demand increased for the grandmothers by individuals and groups throughout the city who respected the value of their presence and input. The requests far exceeded the grandmothers' ability to respond, and at times there was too much intrusion into the project when they would have preferred to keep it informal and focused on enjoying one another. Yet the attention, honour, respect, and acknowledgement they were receiving was both affirming and rewarding.

4.3.5.1 Willingness to Influence the System

"I'm getting to understand . . . that the system has to be changed."

The project became involved with the health care system at a policy-making level through participation in the health district's Aboriginal consultations. Following the first all-day workshop between Aboriginal

202

people and the health district board, and subsequent work on the follow-up Aboriginal subcommittee, one of the grandmothers observed:

> I, myself, am starting to understand, because I didn't quite understand their system. But now I know, since we've been involved [in the subcommittee], I'm getting to understand that I, myself, feel that the system has to be changed if they want the Aboriginal people to get involved and this is what's happening and I'm very thankful for that, my involvement with it.

The staff and I organized opportunities for the grandmothers and encouraged them to engage with the health care system at an analytical level and to take the perspective that they had both a right and a responsibility to participate in changing and improving the system. For most, this was the first time they had been part of the system as anything but a patient or consumer of services. Through the project, they spent time examining the system in light of their own experiences, needs, and their Aboriginal beliefs, traditions, and practices. They were invited to meet with decision-makers and express their opinions and suggestions. When the subcommittee met with the health district board at one of its regular meetings, the grandmothers sat quietly yet supportively, their presence lending an air of strength and wisdom to the presentation.

An oft-repeated suggestion for improving the health care system came from one particular grandmother and was endorsed by others: hire and train Aboriginal community health workers, like the community health representatives (CHRs) on the reserves, to work in the urban neighborhoods with Aboriginal people. These employees would serve as front line workers, advocates, and would liaise with and gain access to the health care system which was often found to be unreachable, bewildering, and impenetrable.

By having closer contact and a more analytical look at the health care system, the grandmothers began to judge it in terms of their own needs. As before, they often found it lacking, but now they started to articulate how and why, and consider improvements and changes. They now had an indirect line to the decision-makers and had the satisfaction of knowing their opinions were being heard at that level. By the end of our funded

project, the Aboriginal subcommittee had lobbied successfully for Aboriginal people to be allocated two of the six newly appointed health district board seats. Access to decision-makers became more direct.

"I'm getting to understand that the system has to be changed"

You mean it's not all-knowing?
You mean the docs aren't kings?
You mean they can't cure all?
You mean we're not just things?

Of course I knew all that.
It's just that once inside
I'm sick and small and lost
and feel I'm weak, I hide.

But now that I can face
and now that I can see
the big wigs at the table
they're just the same as me.

4.3.5.2   Reaching Out

Individual grandmothers reached out and got involved in community activities from contacts made through the project. An example of one such connection was made through the monthly community networking luncheon which brings together city programs working with Aboriginal people, and are held at the Aboriginal community centre. Each month, one program is the host. When it was our project's turn, one of the grandmothers went with our staff and spoke about our goals and activities. As she finished, staff from a home for unwed pregnant adolescents approached her and arranged for her to speak to their residents about parenting skills and Aboriginal traditions.

There were numerous other connections, some of which involved individual grandmothers. Two of our grandmothers were regular volunteers at a neighborhood police centre, an experiment in community policing. Their involvement strengthened our project's connections with the city police in their community development efforts, especially with children at risk and slum housing. Four other grandmothers volunteered

to make quilts for an inner city health clinic's young parents' project. Our project had formal connections, too, with various agencies and events, initiated by one side or the other, and our grandmothers were regular sitting members of several committees.

Because ours was a health promotion project and the newly created health district had jurisdiction over health services for the city, the project devoted considerable commitment to consultations with them. The first major event was a full-day workshop with all health district board members and some staff and invited Aboriginal representatives. At the next Tuesday morning get-together, some of the six attending grandmothers commented:

> We all enjoyed it and thought it was a success.
>
> I didn't even get bored. It was my first ceremonial round dance.
>
> It was my first time in such a group and it was good.
>
> I think we're on to something and off to a good start.

Four of our grandmothers continued on the follow-up organizing Aboriginal subcommittee and their participation was regular and ongoing.

Near the end of our project, the health district's community development staff person, who facilitated the Aboriginal subcommittee, nominated the grandmothers for a health promotion award. She wrote of their role on the committee:

> They have been strong advocates for a focus on holistic health development and health promotion. Their personal growth through participation has impacted on their own well-being and that of their families and communities. These women touch the lives of many more.
> This project has offered guidance and wisdom to many agencies and initiatives. The [grandmothers] have been tremendous resources for the work of [the subcommittee] . . . They are keenly aware of the struggles Aboriginal people have in regards to health and well-being and they share their insight and ideas for improvement.

There were other examples of the grandmothers reaching out beyond themselves and their own personal interests. At a civic government level, the project staff and grandmothers were involved in two annual consultations that the city council held with Aboriginal people. The provincial health council conducted goal-setting consultations and several of our grandmothers participated. The local Aboriginal high school regularly invited the project to their events and we invited them to our special events. An international development agency often included us in its activities: a forum to discuss indigenous rights; a retreat on environmental issues; and a workshop at a Metis historical site on community health development.

Many groups sought advice from the grandmothers in our project: an American foundation, for a book chapter on mid-life and older women for an upcoming book; a neighborhood community association with its interest in children at risk; a diabetic education project in its planning stage; a midwifery task force on the grandmothers' birthing experiences; a cervical cancer study; an urban planning initiative for children; a church-based youth orientation program on inner city issues; and a television mini-series on seniors.

The grandmothers' awareness and analysis of some issues they deemed important increased through their contact with the project. Noteworthy was their interest and involvement with the proposed nuclear waste disposal, that was triggered by a workshop co-sponsored by the international development agency which several grandmothers and staff attended. The following Tuesday, those grandmothers reported back to the others about the workshop and particularly about the discussion on spent fuel storage. From the reaction of all the grandmothers, it was obviously an issue of visceral concern. To better inform themselves of the situation, they asked for speakers to come to one of our Tuesday morning get-togethers, they attended an evening discussion with a South Pacific woman who was fighting nuclear weapons testing in that region, and they went to another evening at the public library to hear a Native American activist speaking on nuclear waste storage on her home reservation.

Another issue the grandmothers regularly mentioned as being important was HIV/AIDS, so we invited an Aboriginal woman to speak to our group. She had been active with Aboriginal AIDS initiatives since nursing her son on the reserve until he died from AIDS. With her, we had an all day workshop, also bringing in a counsellor who had done work with AIDS in the north of our province with Aboriginal people. Towards the end of the day, one of the grandmothers said: "It's important for the grandmothers to hear her story so that as more people come out with [HIV/AIDS], we have to know what to do." They all agreed that grandmothers could be influential in accepting and welcoming back to the communities those afflicted by AIDS.

In the southern part of the province, a group had formed of both Aboriginal and non-Aboriginal older women. Twice, they invited our grandmothers to workshops they were hosting in the south, and in turn we hosted them at a lunch when they visited our city. After the first trip south for a workshop on health and personal safety, our grandmothers reported back at the next Tuesday morning get-together. Beyond all agreeing it had been an enjoyable experience, they repeated a common observation:

> White ladies [as met in the workshop] have the same problems with children and stress. Their problems are the same, and their diseases are the same--basically, we all have the same problems--being alone and dealing with health issues.

Two years into the project, the grandmothers were able to shift from expressing personal, immediate concerns to sharing with others individually or in a small group, such as by publishing their teachings in a calendar. A year after project closure, they invited the community to come together for a workshop to extend their influence and ideas.

reaching out

Turning outwards
reaching further.
Did we know
that others care?

Did we think
that others worry?
Did we see
that others try?
Reach out
clasp warm
hold strong.

4.3.5.3   Speaking Up

"As grandmothers, we have to speak up . . ."

In numerous situations, given opportunity and encouragement, the grandmothers expressed an interest and a felt need in becoming activists, in "having a voice."   They wanted to articulate their views and act on their beliefs so as to influence opinion and decision-making on certain issues.

When the new provincial health council was conducting community consultations to establish   health goals, we discussed whether to attend the community meeting scheduled in our neighborhood that evening or request a facilitator to come in to meet with us separately at another time. One of the grandmothers spoke up quickly saying,

> Let's do both, so we'll hear what they have to say tonight then we'll have our own group.

Another grandmother added,

> And we'll do what we did last time [for the health district board consultations] - get together ahead of time and decide what to say.

Then, a third said,

> And then we'll sock it to 'em!

In a different situation, one grandmother was relating her successful experience contesting a health facility's billing for services her family assumed were still under treaty coverage.   She concluded,

As grandmothers we have to speak up for what we don't think is right. It's the idea of it.

When some of the grandmothers and staff attended a workshop on environmental issues, they expressed interest in following up on the uranium mining and waste storage issue:

The thing we can do as grandmothers is to tell the people the danger of this all.

During the presentation at the public library by the Native American activist on nuclear waste storage, one of the other speakers pointed out that our neighboring province passed legislation which prohibits any nuclear waste storage in that province. The grandmothers suggested to each other that we write a letter to our premier asking for similar legislation to be passed here.

At our next Tuesday morning get-together, I reminded the grandmothers of that idea, and they all agreed that we should send a letter. The next week, I drafted a letter, read it to the grandmothers, and got several suggested additions. When we went through the next draft, all the grandmothers signed it and agreed that it should be copied and distributed widely, to provincial politicians, First Nations leaders and bands, Metis leaders and locals, and the press. At a subsequent Tuesday, we all spent time addressing and stuffing envelopes with our letters and sent them out by mail and fax. The local newspaper ran the story a few days later: "Native women urge [the Premier] to ban nuclear waste storage."

During the project evaluation interviews, one of the grandmothers reflected on speaking out about health issues through opportunities created by the project:

. . . with the health [district] . . . we have a chance to express our views, what we want to see, and what our people are going to benefit from . . . Because I think it's high time that the White society listen to our issues which they, themselves, don't even understand what it's all about. But now since . . . we've become involved--there's a few of us grandmothers that are involved with [the health district]--we've come forward and expressed for them to understand us, what it

means, what we want, and this has never happened before. But this is a very good opportunity for us, very good . . .

The grandmothers participated in consultations the city council held with Aboriginal people, and spoke about their views. One of the grandmothers spoke on the importance of personal and community development specifically to increase self-esteem in young people. To determine the need for this work, she said, "All we need to do is pose the question: Do young people feel good about themselves?" She identified the need for more workers to reach the grassroots. She pointed out that some young people with children say: "I don't know how to be a parent." Their own parents grew up in residential school and, subsequently, they themselves "grew up hard." Another grandmother talked of the importance of getting more children involved in recreation. She strongly criticized casinos, which the province was considering putting in the city, and the foolishness of putting more money into addictions counselling to deal with the impact, while supporting the gambling itself.

As the grandmothers expressed in their health assessment, their principal concerns centered on their families, especially the grandchildren. The issues they felt most strongly about, and those they were willing to devote time to, were similarly those that did or would affect the younger generations.

The provincial public health association was publishing a newsletter featuring health stories of community people. Its editorial staff asked if the grandmothers would contribute. There was appropriate material in the data from the project evaluation and participation interviews, so I asked the grandmothers if they would agree to submit some excerpts. They first asked to hear the proposed sections, then agreed to what I read out, saying that it was good to get those comments to others, especially health people who would do well to know some of the grandmothers' ideas and opinions. This newsletter was distributed to approximately 250 people throughout the province.

In one of the healing circles with the grandmothers, I described my son's dismissal, under questionable circumstances, from an alcoholic treatment centre. One of the grandmothers suggested they write a letter of support on his behalf; the others agreed. I drafted the letter, eighteen grandmothers signed it, and we sent it. There was a real sense of solidarity and support around expressing their opinion and challenging a decision with which they disagreed. One of the grandmothers had worked in a treatment centre and knew how things should run. Also, almost all had close contact with addictions problems. Even though I was clearly different from the grandmothers, we had so much in common and such a strong relationship that they were willing to speak on my behalf, particularly since it involved my son in difficulties to which they could relate.

As preparation for the first Aboriginal consultations with the health district board, the grandmothers met several times to discuss the questions put out ahead of time by the planning committee. We agreed to organize our ideas in a paper that could be used at the workshop and in the proceedings to follow, as a permanent record to influence the board. After the workshop, we wrote a letter to the chairperson of the board about the value of the workshop yet emphasizing that ongoing consultations were needed to make change.

The grandmothers had strong, definite opinions on many issues. As a group and to others, they learned that they had the ability to express these views. As Aboriginal grandmothers, they knew they had the responsibility to do so.

"As grandmothers we have to speak up"

> _Silenced voices._
> _But did you ever think to speak up?_
> _Sometimes at home_
> _I would want to_
> _disagree with my husband_
> _but I didn't._
> _Sometimes in town_
> _I would want to_
> _speak up on something_
> _but I didn't._

Now
we're old but we're many.
Now
we're asked and they listen.
Now
we're speaking up like we should.

4.3.5.4   Community Honouring

In many ways, the community acknowledged the value and contributions of the grandmothers, recognizing them through awards, publicity, and invitations of various kinds. Both a national and a local literacy group supported our project to publish stories that the grandmothers told about their early lives.   The media covered the official launching of this book, "Stories from *Kohkom*."†† The title of the 1.5 page newspaper article the next day, "*Kohkoms* share gift of healing," was an apt validation of their role in the community.

The project was the co-recipient of an annual award given to an individual or group that exemplifies the principles of health promotion. The award was established by the local community health department in honor of a physician.   During the public presentation, the grandmothers received a beautiful sculptured plaque with their names inscribed, and their health promoting contributions were described.

The federal government department that supports initiatives of Aboriginal women awarded the grandmothers funding for two projects-- the calendar of their teachings and a community workshop on traditional values.   A minor instance of their recognition occurred when the organizer of the public presentation by the Native American activist on nuclear waste storage held the entire front row of seats for the grandmothers.   The community acknowledged the grandmothers' wisdom by inviting them to sit on various committees, take part in consultations, attend events and functions.   They became a known and visible presence in this city.

Community honouring

Imagine us!
Us old grannies
pictures in the paper
awards in our hands
books of our stories
reports of our health,
But
of course
it's less for ourselves
than it is for the young ones.
Yet
we're really something, aren't we?

This concludes the description of the findings of the effects on the grandmothers arising from their participation in the project and health assessment, and leads into a discussion of the main influence-- participation.

4.3.6   Participation

"The best part is the participation"

In the study of the data for changes in the grandmothers from their participation in the project and research, I identified "participation" as the primary influence on the outcomes described above. Indeed, participation was essential to any project outcome, since the grandmothers had to take part in the project and research to experience any effects. Yet because of the cyclical, iterative, and interdependent nature of so many aspects of our project and research, increasing participation also became an outcome and an indicator of growing empowerment.

The extent of the grandmothers' participation was varied. At its most basic, it meant accepting a home visit from the staff, research associates, or me as a connection with the project and research. Incrementally, the next step was a grandmother attending our weekly get-togethers. Further to that, she accompanied others from the project to a social event or community action meeting. With staff or me, she then agreed to sit on

213

an external committee, and/or speak for the grandmothers on an issue. On her own or with other grandmothers, she represented the project, or her people in general, in activities beyond the project.

The nature of their participation varied as well. Minimally, the grandmothers had passive contact with the project in some fashion. Then they began to speak on their own behalf, either with staff or within the group, and carry out some task in support of activities, such as telephoning the others or organizing the weekly lunch. Further, within the group, they engaged in dialogue and contributed to decisions being made for everyone, first about rather objective matters, like the program schedule and, later, on more personal matters such as disclosing a sensitive topic in the healing circle. A deeper level of participation, both within and beyond the group, was seen as an increasing voice and control over the project and research, and more external connections with the community. Finally, self-determination and ownership of activities and overall operations signified a higher level of participation.

The entry point and the progression for each grandmother depended on many factors. Those who were more isolated and silenced, and others with more traditional language and cultural habits needed individual work with the staff before they were even able to attend the group. Then, as they gained familiarity and trust in the project and the people, they moved gradually from being passive recipients of information and organization to voicing their interests and opinions. Others, who could move between cultures readily and were comfortable socially, were more active and early participants.

This participation was slow to develop, however, and that puzzled me. Early in the life of the project, I commented to our coordinator that many grandmothers were hesitant to speak up, even in our small weekly group. She looked at me quizzically and said, "Most of these women have never been asked their opinion before."

Towards the end of the first year, the grandmothers' comfort level had risen so that most of them were chatting freely and participating well in discussions and conversations.

> The best part is the participation . . . being a participant of that group [of grandmothers] . . . Because they're a part of me . . . and I'm a part of them. It's a wonderful opportunity. That's why . . . I encourage all the other grandmothers to come out and join us, join this group. Supposing that some of us here leave, there'd be all these others coming in, you know. I hope the project stays.

Yet the grandmothers were not always spontaneous in participating in something new. At a Tuesday morning get-together when two different invitations were extended to them by guest speakers for involvement in activities, there was no response. Clearly, in this project and research, because we were trying to change an urban culture of noninvolvement, we needed both to be quite aggressive in drawing the grandmothers out and to not feel discouraged when there was little response. They had to relearn to function in this new environment. St. Denis,[344] in her participatory research in an urban Alaska Native community, also found that a ready interest in participation cannot be expected; it must be nurtured and developed.

By half-way into the three years of the project, the grandmothers began to take on group maintenance functions. About that time, for example, in a Tuesday morning healing circle, one of them (rather than a staff member) reminded the others about confidentiality within the group, other grandmothers played roles in directing parts of the morning, and two others, unsolicited, had brought lunch for everyone.

As introduced earlier, the experiences and background of the grandmothers varied widely and this was reflected in how they involved themselves in the project. Some had never been part of a group or attended a meeting before while others had long histories with organizations such as Native women's political associations; some had limited or no English while others had limited or no indigenous language; some were accustomed to a traditional style of visiting and dealing with a topic in a talking circle format, yet a few had spent many years in

mainstream employment and liked to operate with an efficient agenda and organizational structure. To varying degrees, however, I saw two characteristics that they all shared: a deferral to the group and a discomfort with an individual focus because of their traditional culture, as discussed earlier; and a tendency to invisibility due to, I think, their oppressed race and gender. Participation was a gradual process.

For the project to effectively work with this varied group of women, all of us, including the grandmothers, needed patience, flexibility, sensitivity, faith, commitment, and caring. We were trying to conduct a project with expectations and operating styles that were unfamiliar to the grandmothers to varying degrees.

During one of the evaluation interviews a few months later, one grandmother remarked on project involvement:

> . . . many [grandmothers] have emerged from their shell and have become valuable contributors, . . . and this also includes the contribution of food for lunches and feasts, and they are appreciated by the group. They know that now. Some of them just sat there in the past and now they ask to start [the healing circle] and [they show] a willingness to be in charge of clean-up after meetings.

When I asked for more grandmothers to participate in the project evaluation and participation interviews, one of the grandmothers came to me, holding the hand of another and said: 'What about [a non-English speaking grandmother] for the evaluation? I'll translate for her so that she can be part of the evaluation." She also volunteered to translate for another grandmother whom I had already interviewed in English but who felt uncomfortable with her limited responses; we repeated that interview in Cree. It was noteworthy that she suggested translating so that an interview could take place because such offers were not common in unfamiliar activities such as a project evaluation. If the task had been to organize a feast, offers to help out would have come readily. Increased participation was gradually becoming a group norm.

When I visited one of the grandmothers to leave her a copy of the draft health assessment report, she said:

I feel that these first two years [of the project], we did a lot, but we're just getting started. We can do so much more. I feel strong and want to do so much more (she flexed her upper body to show strength). And it's not for us, but for our grandchildren's generation. We're just getting going. Our circle can be so strong.

The staff and I were anxious to see signs of ownership of the project by the grandmothers that would allow us to gradually relinquish our more directive roles. Incidents of gradually increasing ownership did occur over the life of the project. For example, as the draft of the stories' book was being prepared, one grandmother telephoned me to suggest that the book have a dedication; I wrote this up according to her ideas and sent it to the subcommittee. With the draft health assessment report, after everyone had gone through the first draft, three grandmothers volunteered to keep reading it, beyond our group sessions, until we were satisfied with it. They all devoted considerable individual time to it.

Related to ownership, there were scattered incidents of grandmothers resisting decision-making by staff in the project and exerting more authority themselves. One example of resistance occurred with the project director's decision to alternate the two staff people at the Tuesday morning get-togethers rather than have both attend each week. Her rationale was that the number of grandmothers at each group was small compared to those in the community who were yet to be contacted by the project. A few of the regular group attenders argued about this decision for months until the director relented.

From my first thwarted attempt at doing PAR and from writings of Gerrard,[345] [346] I had learned to look at resistance constructively. In this project, therefore, I was able to take the perspective that we could feel pleased that decisions the grandmothers had not been directly part of were being challenged by some of them. This indicated self-confidence, ownership, and empowerment. Disempowered women would not feel they had the authority or right to be challenging; many might not even have the inclination.

Doing our health assessment in an explicitly participatory fashion
enhanced the tendency for the project overall to be participatory. Over
the course of doing the health assessment, there were numerous examples
with the grandmothers of group involvement, participation,
identification, trust-building, and accountability. One of the
grandmothers was concurrently involved in another community
research and development project that was running into resistance from
the group with whom it was formed to work. During our project
evaluation and participation interviews, I asked this grandmother to
reflect and comment on our project and research in relation to the other.

> [In our work with our health assessment and consulting with the
> health district board] . . . the best part was getting the people,
> getting the older women involved because I feel that older [women],
> such as older than me, those are our guidance and always have been.
> We go back to the older persons, because an older person has so
> much to offer and this is what the [health assessment work which
> led to consultations with the] health district board did, really got the
> older women involved, which is really good and [we] did an
> assessment the respected way. So this is why [we] don't have any
> problems today. We don't. Everybody seems to be going in the right
> direction.

Two years into the project, at a Tuesday morning get-together, we had a
group discussion on the health assessment framework and content, after I
had got everyone's individual comments in their homes. The
grandmothers approached the task seriously and thoughtfully,
participating fully. It was encouraging to see how well they were
relating to this phase of our research, which signified to me that they
were interested because they saw value in the activity.

Another initiative, the project evaluation, afforded an opportunity for
the grandmothers to participate in an assessment of the project and
suggest areas to emphasize or change in future programming . When I
had analyzed all the project evaluation and participation interview
responses, I used a Tuesday morning with the grandmothers to review the
themes found, backed by supporting quotations. The grandmothers
listened with rapt attention to what they had said collectively, eloquently,
movingly, and humorously. At the end, one of them said, and the others
nodded, "I'm just bubbling with joy to hear all our words."

Participation is a cornerstone of PAR and health promotion, yet may be difficult to achieve. In our project, we learned that it had to be nurtured patiently and deliberately, but if done so yielded satisfaction and success. Looking at the process and products of other initiatives that were less diligent about and committed to active, genuine participation, we were able to see the practical value of our attention to it.

"The best part is the participation"

*We did our assessment
the respected way.
It was the older ones
who had their say.
We took our guidance
the respected way.*

4.3.7   Action

In this model of findings from the project and research, I identified "action" as the theme that weaves throughout. Like participation in our cyclical and interdependent work, action, though a philosophical principle, can also be viewed both as an influence and an outcome.

In section 3.1 in "Action taken," this theme is introduced. Throughout this document, examples are given of actions taken by the grandmothers, staff, and me both in response to insights and needs that emerged and also to provoke movement and change at an individual, group, and community level. Actions included innumerable examples of the staff and me advocating for grandmothers and supporting them to advocate for themselves; of the grandmothers connecting to and assisting each other and contributing to the development, cohesiveness, and identity of the group; and of all of us reaching beyond the group and its immediate issues and being active in community initiatives.

219

Action

No, we don't just sit and talk.
No, some things are not so good.
Yes, we want our voices heard.
Yes, we'll speak and work for change.

4.3.8 Environment of Opportunity, Encouragement, and Mediation

The final aspect of the model is the project and research environment created by the staff and me initially, but then enriched by the active presence of the grandmothers. From studying the data in regard to the milieu in which we operated that contributed to empowerment outcomes in the grandmothers, the key characteristics that emerged were opportunity, encouragement, and mediation.

Opportunity refers to creating favourable social spaces and moments in which growth and development can take place, examples of which were numerous. Regular experiences were organized for the grandmothers to deepen their understanding and ties with cultural traditions and practices, and others to provide for their healing and personal growth. Bringing in speakers to address various issues of concern, such as veterans' spousal benefits, child tax allowance, nutrition for diabetics, and family violence strategies gave the grandmothers a chance to get questions answered and connect with available services. Consultations were arranged so the grandmothers were able to voice their opinions to policy-makers on health and social issues. Moreover, the entire project and research afforded an opportunity for the grandmothers to build a community among themselves to further develop and share their own capacities.

Encouragement refers to the tone the staff and I set of explicit faith in the grandmothers' worth, capacities, and potential to pursue individual and collective development, and the tone they set for each other once they felt comfortable in the project. An example of encouragement was the role the grandmothers, staff, and I played with each other in the

220

healing circles.   By our obvious caring and compassion, each woman in turn was encouraged to unload the worries and pain she was carrying, or share a joy that brightened her life, and in doing so find relief, comfort, and healing.   In a more concrete instance, a grandmother was encouraged and supported to write a letter and make telephone calls which successfully challenged an institution's incorrect billing of her invalid husband's day care program expenses.

Mediation is a role the staff and I played with the grandmothers initially, and they played with each other later, bringing about connections and communalities among them, then linking and acting like cultural interpreters between the group and external bodies and events, and also in negotiating problem-solving with them as individuals and a group. There were countless examples of mediation.   One occurred when a grandmother suggested working with me as a cultural broker to conduct the project evaluation and participation interviews with two grandmothers who preferred to use their native language, as described previously.   Another was the project coordinator negotiating with the telephone company for installation of phones for grandmothers based on emergency medical needs.

Environment

Support--challenge.
Comfort--nudge.
Come together
feeling safe
in warm connection.
But more.
Abilities
issues
chances
responsibilities.
With support
of each other,
give expression,
strengthen all.

This ends the presentations of the findings on the areas of change of the grandmothers, who were the primary subjects in this research, as outcomes of their participation in the project and research, as depicted in

the model. Since the staff were active participants in this initiative as well, some consideration of their views and the impact of the project and research on them is warranted (effects on the ER were presented in section 4.2). Those findings are summarized in the next section.

4.3.9 Effects on Staff

The interviews with two of the project staff members did achieve their intended purpose, as identified in the methodology section, which was to contribute to program evaluation, examine the effects of involvement on the grandmothers and themselves, and provide an opportunity for staff to critically reflect upon their experience and learning in the project and research.

The staff described differing degrees of familiarity with community development and health promotion, both in theory and practice, prior to the project. Neither knew anything about PAR until we started our work together. Their roles and tasks were many and varied but the pervasive ones were facilitation and management.

The staff identified participation as the important element which led to visible outcomes in the grandmother.

> The grandmothers' participation . . . was one of the major things that happened in the project and I think the timing was just perfect for what we did with this project and the participatory action research.

From their perspective, they mentioned a number of changes they had seen in the grandmothers over the course of the project period, notably emerging from shy, quiet women to being able to express themselves within the group and beyond.

> She came into the group, and hardly talked . . . for a long time, and once she started, she attended all our group sessions and she participated, did say a lot of things, and in the healing groups that's where she started really talking. And I think it did her a lot of good, and she still is doing a lot of talking now.

222

Some of the grandmothers had never been to meetings . . . and they were participating. That was a big change for them. . . . Yeah! There was evidence [of empowerment]. They were not afraid to speak their minds . . . to express some of their needs to the ministers . . . some dignitaries would come along and they were quite capable of doing that.

There was further reflection on the grandmothers' empowerment.

It took a little while for them to even believe what we were initially telling them--that people wanted to hear from them . . . their opinions. And I think in the beginning, they thought we were out of our minds. Eventually, they did decide that maybe we were accurate and they began to feel comfortable doing that. I think also, some of them maybe began to try, in small ways, to be more assertive about their own needs within their personal lives, try out little measures of independence and . . . for women as a whole that is probably a harder thing to do than speaking out publicly because I think in some ways it is more of a risk [to] assert your independence within your own family situation.

Other positive outcomes of the project for the grandmothers were noted.

[It was] a 'time out' for women, for their own self-care and personal healing . . . and it went a long way to breaking down the social isolation. The high points [were] the particular celebrations, the occasions in which the grandmothers formally spoke out, the trips they took together, the things where they celebrated their culture-- their feasts.

The staff were able to identify growth and learning that they had experienced in terms of their increasing knowledge of community development, health promotion, and PAR, and their personal and further professional development in general. They spoke of the benefits of working with older people and elders, and learning from them the traditional teachings and skills. One spoke of developing a "wider view" in her thinking about many issues, and really "starting to understand community development." She talked of her own empowerment:

I do have power and can affect the world around me, and I'm capable of organizing and facilitating groups, or talking to individuals about a project . . . and I can make change . . . I can present my point a lot better than I used to. The support that I got [in the project and research] really, really made a change. In myself, I was more trusting, . . . more assertive . . . in a good way, and I was able to practice some of my skills where I wasn't scared that I was going to

223

be wrong. The healing circles [were] a positive change for me, and the openness of the [staff] working relationships. I thought we all learned from one another which was good.

The other discussed her learning in relation to community development.

[Labonte's] sphere (described in the next section, 4.4) is a much more appropriate way to depict [community development] than a continuum because there always had to be bits and pieces of everything, even when we got to the end of our three years of funding. We were still working at the personal care level and part of that was because we had a transient group, so we were continually adding new people but also because these women were living in daily crisis and sometimes they needed to focus in on more of their personal needs and . . . issues and did not have the capacity or time or energy for some of the community activities they were genuinely concerned about and committed to. The project confirmed in a very profound sort of way everything I thought I knew about community development.

The staff were able to identify difficulties, problems, and limitations of the project as a whole, including limited involvement of the rest of the sponsoring agency, absence of an elder, intrusion of money matters, changing the healing circles, and the constraints of time.

We invited him how many times? [The administrator who] never came. . . . and the board, I think we got one person. We should have had more people [from the sponsoring agency] involved.

We should have had an elder . . . That would have helped the group plus some of the individuals that were quite ill--they were in need of an elder.

The money the [grandmothers] were fundraising, they didn't know what to do with it. I think that they were more confused about what to do with their [money] and [it] kind of separated the whole group. . . I think the money played quite a role there, but we didn't know that. Here I was trying to fundraise all the time.

One of the things that really deteriorated the success was when we kinda let the healing circles go, when we started to change [them].

We always felt under terrible time constraints. Sometimes we would forget to honour the community development process and we would start pushing a little too fast for the grandmothers to take more ownerships than they were ready to take.

Cultural and age differences and respect for these posed a barrier, as well.

224

I was so very, very sensitive from the outset that I was not of the culture. I was a White health care professional and I was so very eager to never speak out of turn and to encourage the leadership to develop within the group and it did not . . . as quickly as we needed it to and when conflict arose . . . you [ER] and I did not think it appropriate for any one of us to try and take a leading hand in intervening--that the intervention needed to come from the grandmothers themselves, if in fact they were perceiving these problems and were concerned about them. . . . Also, I was very much caught up in the notion of respecting [my] elders, too. Well, of course, as we discover now, after the fact, the [grandmothers] voted with their feet by withdrawing, in one way or another.

When asked about the participatory health assessment, the staff spoke of their satisfaction with the methodology. Their initial impression had been that PAR would fit well with the community development and health promotion approach of the project, and now they continued in this belief.

I certainly am equally convinced of that--that it is an excellent approach in terms of really meaningfully involving people, empowering them through the process that we are all engaged in. . . . On the day I sat in when you [ER] were reflecting back, on some of the things that were gathered during the individual interviews, I saw that as a really wonderful day. I saw the [grandmothers] feeling really encouraged and excited about all the strengths that they did have from their cultural background and things that they could still use and draw on. I think it was very affirming for them. Those opportunities to practice expressing themselves are the kind of thing that strengthened and prepared them for making that presentation to a government official.

Our Aboriginal staff person spoke about how PAR looked from her cultural perspective.

I think it's one of the best ways to do research because of the involvement that is so unique and the people themselves are doing it. They are not feeling as if they are being researched. We are not hearing what the [grandmothers] want us to hear, we are hearing what they have to speak, and a lot of time with other research they just tell you what you want to hear. I really enjoyed the way that we did it, because the participation was structured but yet it wasn't too heavy. Especially with Native people, . . . it was the flexibility that really got their interest.

This staff person discussed how the PAR experience has altered her own views of research.

Before it was very negative to me. Like some of the grandmothers were saying "we're tired of being researched," but now I look at it more positively, because . . . we need to do research before we can make changes, because we need to know if there's after effects, or what the after effects will be, or is this the right thing for these individuals. Before . . . research was done quite differently, and it wasn't good at times, because they did research all in offices, but this time we are going out in the community and doing it--like what we did--in participatory action research, people just got involved in it which has made a significant difference because now we really know what [the grandmothers] need.

She commented further on our attempt to use local research associates.

I thought that was a good idea. It was an excellent thing to do because that is building community, and I thought that we were trying to do that, and to give other people a chance to come and do a little bit of work, and plus the learning.

Yet the benefits of PAR were moderated by the limits of project time and the grandmothers' reduced capacities.

The [grandmothers] showed in a number of different ways they had the capacity, the desire, and the willingness to develop their skills and their abilities and their knowledge according to the PAR model but they had an awful lot of constraints on a daily basis in being able to sustain their interest and their motivation and we were terribly constrained with how much time we had to work them.

In retrospect, the staff identified some areas that could have been improved and other strategies to be employed to foster greater empowerment and community building in the grandmothers, such as more explicit conflict resolution guidelines, emphasizing more traditions and healing circles, and having larger community meetings to get broader input into the grandmothers' situations.

This completes the reporting of the analyzed findings of the research on effects of participating in the project and research. The next subchapter, 4.4, discusses these findings further, specifically in relation to the nature of PAR and health promotion.

4.4 Discussion of Effects on Participants of Participation in the Health Promotion Project and Participatory Health Assessment

This subchapter considers the findings related to the primary research objective regarding effects on the grandmothers of their engagement in the project and research. As presented in the model in the preceding subchapter, I grouped the data on changes into five categories. Participation is presented in the model as the primary influence on the outcomes, action as the interweaving theme, and opportunity, encouragement, and mediation as major indirect influences of the project and research environment.

Speaking to those findings, this discussion section starts with further reflections on the categories of outcomes and on the staff interviews. Commentaries follow on participation, action, and the elements of the environment, and the phenomenon of "silence" is introduced in acknowledgement of what the grandmothers did not say. Then, the findings are looked at as characteristic of empowerment, and in relation to a model of empowerment in health promotion practice. Finally, the trustworthiness, subjects, and limitations of the research are considered.

4.4.1 Further Reflections on the Categories of Findings

The effects of participation in the project and research were apparent in the grandmothers by their exhibited attributes and behaviours. These changes were apparent at both an individual and a social level, at a personal and a political level. They experienced cleansing and healing, connected within themselves, acquired new information and skills, connected with each other, and became engaged in activities external to the project. Furthermore, they undertook numerous actions in response to their identified needs. These effects as outcomes of participation are consistent with and descriptive of growth and empowerment. The purpose of this discussion is not to measure outcomes or pass judgement but to further the formative learning process about participation in health promotion.

Cleansing and healing, and connecting with self

> It is quite clear that no social reform, no beautiful constitution or . . .
> programs of laws will be of any consequence unless people are
> healthy enough, evolved enough, strong enough . . . to understand
> them and to want to put them into practice in the right way.[347]

Healthy societies are composed of healthy people. Thus, consciousness-raising in PAR and health promotion is concerned just as much with personal growth and the realization of individual capacities as with socio-political issues and change. Through their participation in empowering research, learning, and organizing, people discover their potential and use it. Personal healing and connecting to self, as the grandmothers experienced, are fundamental to what is called "transcending behaviour"--"the development by people of the capacity to transcend their limitations through constructive and creative action based on a new perception of themselves and a new vision of their future."[348]

In the health promotion field, personal growth is part of empowerment. It is important to clarify, however, that in this study empowerment does not mean only that power is transferred from one person to another. More often, empowerment indicates a process that starts from the inner self, "power from within," generated by a power that already exists within the person, although commonly unrecognized. Empowerment or growth summons, nurtures, and fulfills what is already there but was not realized and/or was latent. In our project and research, empowerment was further actualized by the egalitarian "power with" relationships established among the grandmothers, staff, and me in negotiating and conducting the health assessment. Without explicitly contrasting ourselves to the conventional power imbalances between researcher and researched, we operated within a different relationship. In these "power from within" and "power with" roles, the grandmothers found their voices and began to more fully engage in the research process. Such an experience fostered a "mutually educative encounter"[349] that raised the confidence, skill level, and consciousness of the grandmothers, staff, and me.[350]

228

"Personal healing" and "connecting to self" describe human growth, which is the capacity to become something different, to discover oneself, to experience power, to recognize an ability, and to develop.[351] It is a transformation of the total person: "an expansion of self including the release of inner tendencies for good; a steady increase in self-acceptance and understanding of others; the use and enjoyment of talents; an increase in autonomy; and proceeding from all of the above, a greater power to alter and shape the environment."[352]

For the grandmothers, the cleansing and healing processes were most often experienced in the healing circles, and felt clearly by the speaker of each story and by the others. A central element of the circle is self-disclosure: "telling one's story, voicing one's suffering, finding the words to express it, sharing."[353] "Its power lies in people speaking from the heart of their experiences, without the threat of interruption or disagreeing challenge."[354] The resonance between the speaker's pain and the listeners' compassion fostered catharsis, and contributed to healing and building relationships and group cohesion. Connecting to self describes the tie among all parts of the inner self, based on the belief that the inner self is whole and is the core from which all life unfolds, including action.[355]

Beyond the healing circles, other connecting-with-self processes were less distinct and defined, more interwoven throughout all project activities, and honoured the grandmothers' Aboriginal identity. These included feasts, sweet grass smudging, use of a speaking stone, planting of a project tree at an Aboriginal heritage site, round dances, contact with elders, and discussions of the medicine wheel and other beliefs and practices. They served to anchor the project in valued Aboriginal culture and history. The grandmothers had varied familiarity with these beliefs and practices but most were interested, respectful, and responsive to their inclusion. For many of the grandmothers, the project afforded the only connection with tradition and a unique opportunity to increase their pride in their Aboriginal identity and heritage. Occasionally, we would be honoured with the presence of an elder at one of our functions.

Otherwise, the grandmothers sought guidance from one another, serving as mentors and counsellors for each other.

The individual interviews, both for the participatory health assessment and for my research on the effects of participation, provided valuable opportunities for connecting with self by the grandmothers. The sessions were devoted to and focused on a grandmother's past and present life and on her involvement in the project, validating her experiences, opinions, and wisdom, and fostering a reconnection with her values, traditions, and strengths.

In the PAR literature, personal development is not emphasized, yet it was the healing circles, individual home visits, and traditional ceremonies that were the powerful strategies for change with the grandmothers. PAR emphasizes raising consciousness on socio-political matters which affect the individual. It seemed to be more effective with the grandmothers to address individual healing and growth and allow change from that attention to foster their critical awareness and interest in social action. This approach emerged from what worked with the grandmothers, and was grounded in the belief that each could participate in social concerns when her own individual needs were being addressed. When the grandmothers did not respond to problem-posing questions and attempts at critical social analysis and reflection, the staff and I would realize anew that more time needed to be maintained on the individual and group levels.

The focus on personal development complements and fosters consciousness-raising and socio-political action. It lays the foundation for that group commitment and action by developing in people greater self-knowledge, self-love, and self-motivation which are "arguably the essential prerequisites for enduring social change."[356] After individuals have received support for their crises and achieved relief from their pain, many "are willing to become involved in community or social action, to help change certain aspects of their social structure, set up new programs or services, fight for new laws or changes in legislation, lobby for more research, or raise money for their cause."[357]

230

Increased self-care was an outcome of the grandmothers' participation in the project and research. Self-care is "the art of acting, for oneself and by oneself, on decisions regarding which of the five basic resources to use" (oneself, the environment, others, professionals, or information) to satisfy the five basic human needs (physiological, security, love and a sense of belonging, esteem, and self-actualization).[358] Each grandmother demonstrated care of herself in different ways, but common to all were indications of self-worth and self-respect.

The difficulty the grandmothers had in recognizing and naming their strengths in the health assessment indicated a diminished and/or dormant connection to self. Through the extended period of doing the assessment, they demonstrated a gradually growing self-appreciation, and an ability and willingness to articulate and advocate for and about themselves. As part of a marginalized group in terms of race, gender, and socioeconomic status, these women spent their lives taking care of others, giving little thought to themselves in comparison, and often being treated by others like second class citizens. Developing the ability to see resources in themselves and beginning to speak out on their own behalf were real indicators of growth and empowerment, even if the grandmothers often framed their words and actions in terms of improving conditions for their grandchildren rather than for themselves.

The variety and richness of the grandmothers' involvements were curtailed, however, when the project closed. The grandmothers deserved support over a longer period of time, both for recognizing what change was possible and for continuing the validation and growth already started. Our work, as is often the case in community development, was not supported long enough for this growth to bear the fruit of its potential. Lord and McKillop Farlow[359] also found in their study that elements helpful to people in gaining control and participation in life featured resource support as prominent. Berger[360] draws an analogy:

> For the seed to germinate and to sprout, water and heat are not
> enough. A certain amount of time is also necessary. The gardener

who looks at a green apple will not say that it lacks sugar but that it needs days to ripen. It is not enough to cultivate and irrigate. One must also know how to wait. When all the work is done, it is still necessary that the seed underneath pursue its own destiny.

As one of the grandmothers said (quoted in full in section 4.3):

. . . We can do so much more. . . . We're just getting going. Our circle can be so strong.

Acquiring information and skills

The grandmothers came to the project with a lifetime of knowledge and skills built up from traditions passed onto them and from their own personal experiences growing up and into adulthood, as mothers and grandmothers, and as members of their home communities. Most, however, were displaced from their familiar environment, involved in new responsibilities, dependent on institutional avenues of support, and facing challenges unknown to previous generations. The project and research played a role in validating their own strengths, creating a safe place to work through lingering pain and current problems, and assisting them with knowledge and skills to cope with their new setting. In this last area, despite the constraints of project time with the grandmothers in both duration and intensity, progress was made as the study data demonstrated. In the midst of contemporary challenges, the grandmothers learned more about self-care and existing resources and how to gain access to them. They became more comfortable naming and speaking out about their opinions, strengths, and concerns. They developed interpersonal connectedness--learning to build a community with each other, and altering their perceptions of commitment and responsibility to others, notably family members. They experienced building partnerships within the urban environment, and recognized the impact they could have together with others.

Yet given the project constraints, some knowledge and skills were inadequately addressed, including improving physical fitness, critical thinking, decision-making, goal development, social analysis, conflict

management and resolution, and longer-term community involvement for policy development and political change.

Connecting within the group

The structure and function of a group may facilitate growth and empowerment of the participants. Interactive group dynamics provide individuals scope for expressing themselves, being heard, being appreciated, being honoured, being validated, making a difference, and belonging to a community. The group is an intermediary phase between individual growth and a wider world role.

Despite their differences, the grandmothers of the project displayed two common characteristics, introduced in section 4.3 but important enough to be mentioned again: first, a deferral to the group and a discomfort with an individual focus because of their traditional culture; and, second, a tendency to invisibility likely due to their oppressed race, gender, class, and age. The grandmothers found it uncomfortable and inappropriate when one of them was singled out to receive attention, credit, or praise, given that the value of the whole social unit was priority and of more importance than the attributes of any one individual. Despite the critical need for individual healing and growth, and the worth of one-on-one relationships and intervention, all development had to be situated in terms of the norms, benefits, and acceptance of the group. This cultural trait alone would not suppress an individual voice but, coupled with a history of racial oppression and a more contemporary experience of gender oppression, resulted in the grandmothers feeling they had neither anything of worth to say nor any social space for expression--the culture of silence of which Freire speaks ("silence" is discussed again later in this subchapter).

The beneficial effects of participating in the project and research for the grandmothers can be partially attributed to the value of what may be called mutual aid. Romeder[361] wrote and edited a small publication exploring the self-help and mutual aid movement. It is so relevant to our project and research that I use it extensively here to examine our

findings in this section. In its foreward, Everett Koop, former United States Surgeon General, writes that the "sharing of common experiences through mutual help groups, particularly if there has been great hurt or suffering, unleashes something very special in the way of healing, as people who have known its effects will attest."[362] Professionals who are skeptical of this movement, accusing it of "the blind leading the blind," see transformation, change, and healing as their domain because of their specialized training, knowledge, and techniques. Koop argues that the blind can indeed lead the blind.

Mottoes and characterizations of self-help groups include: "You alone can do it, but you can't do it alone;"[363] "In self-help, you get help, you give help, and you help yourself;"[364] we help "ourselves by helping others;"[365] and "Health not only resides within us as individuals, but between us."[366]

Much of the benefit the grandmothers reaped from their participation in the project and research came from their association with each other. The project and research provided the vehicle for them to come together, and realize their own and collective resources. Others who met with the grandmothers inevitably commented on the presence, wisdom, stability, affection, humour, and *joie de vivre* they embodied. Besides socialization, recreation, friendship, and reclaiming culture, the group satisfied two other types of needs for the grandmothers: help in dealing with a crisis or serious difficulty while realizing they were not alone in their experience; and a sense of control and individual involvement in issues which affected their lives, in contrast to being dependent on impersonal, rigid protocols of institutions and professionals. The common trigger for mutual aid is the pain experienced from crisis; its relief, similarly, is found through mutual aid. The grandmothers, through their involvement in the group, became more empowered--"they discovered how to regain control of their lives and rediscovered hope as well."[367]

The structure and function of the get-togethers in our project and research met many of the criteria and functions defined for self-help groups:[368]

- small, open groups that meet regularly;
- participants share common experiences of suffering, including the feeling of being a victim, isolated, rejected, or excluded, which resonate with others' responses;
- participants meet each other as equals, measure their own experience, observe role models, and make new friends;
- the primary activity is personal mutual aid, a form of social support that focuses on the sharing of experiences, information, and ways of coping;
- in addition to personal change, participants often engage in activities directed to social change;
- activities are voluntary and free;
- the focus is on participants' health, strength, and capacities to foster growth;
- the aim is for meaning and acceptance of what has occurred, and creation of optimum ways to cope in the present.

The grandmothers, through their participation in the healing circles and many other project and research activities, gave and received mutual aid, focussing on each other's emotional, behavioural, spiritual, and social problems, as well as their traditions, joys, and sense of humour.

External exposure and engagement

For many of the grandmothers, the interpersonal connectedness with external individuals, groups, and initiatives as part of the project and research were unique and empowering. Sections 3.1 and 4.3 described the nature and extent of those contacts and the impact on the grandmothers. A case example of one grandmother is included here as illustration.

M. is in her early fifties, in good health, and with all her children and grandchildren living away from home except during special visits or times of difficulty. Although she held a job outside the home while she raised her six children alone, she had had virtually no other contacts or involvements. She joined the project and research in our second year

235

and thereafter regularly and actively participated in the activities. She was "young," yet became the spokesperson for the grandmothers on several occasions toward the end of the project because she was composed, interested, and capable. In speaking to her recently, she was the picture of enthusiasm and confidence, and animatedly recounted the activities she is now engaged in, marking the shift to community involvements from the time she joined the project:

> Before I never did anything outside the family and work. Since the grandmothers' project and research, I teach crafts at the Aboriginal heritage site, sit on the steering committee of the children's coalition, have been trained as a guide for Aboriginal art shows, and helped start the urban First Nations healing initiative.

Staff perspectives

The data from the staff interviews, collected a year after project closure, triangulated the findings from other sources. Indeed, the staff highlighted the central role of participation in the project and research, and the changes observed in the grandmothers which indicated empowerment. Also, similar to the unique, active, participatory role of the ER, the staff, too, felt central to the project and research and experienced benefits of their own both personally and professionally.

It was validating to hear the non-Aboriginal staff person articulate the same self-censorship I imposed on myself in our common effort to be culturally sensitive and avoid playing the "ugly oppressor" role which we implicitly represented. Regarding PAR, it was gratifying to hear opinions from both staff members about the appropriateness and effectiveness of the participatory health assessment. Worth noting is the shift in the Aboriginal staff person from her position of resistance to research to one of appreciation of its function and value when done participatively and flexibly. She called the research "flexible," meaning that it was integrated subtly into other project activities and that some data collection was done indirectly, rather than the whole initiative being too structured, obvious, and demanding.

The findings from the staff interviews were not new to a large extent but were valuable in validating findings already identified from earlier data and in underlining the worth of PAR from others' perspective.

4.4.2   Commentary on Participation, Action, and Elements of the Study Environment

Participation

Participation, considered the central influence of the outcomes found in this study, is a cornerstone of PAR, health promotion, primary health care, community development, and people-centred international development.   In the philosophies of these movements, there is, arguably, no principle that is more sound than the emphasis on participation. People have the right to be part of the formation of their own paths which direct their activities and ultimately their destiny.   From this perspective, it is more important to emphasize building people's capacity for participation over time than achieving other specific results. Effective and sustained participation, by way of developing human potential, requires opportunity, experience, confidence, skill, positive reinforcement, and support.

Attesting to its importance, current emphasis is given to participation of communities[369] in program planning, implementation, and evaluation; research; education; policy development; and decision-making.[370] [371] [372] [373] [374] [375] [376] [377] [378]   Participation was introduced earlier as a quality of PAR, and is expanded upon here because of its central role in the findings of this study.

Definitions of participation are varied, starting from the minimalist, consultative, "pseudo-participation"[379] end of the spectrum to the maximum, liberatory, participant-control type, as is advocated in this study.   For Freire, participation heralds development in which people, previously treated as objects, participate in their own humanization-- becoming active subjects of knowledge and action.   Fals-Borda speaks to its overall aim in redressing oppression: participation is "an egalitarian

237

philosophy of life designed to break unjust or exploitative power relations and to achieve a more satisfactory kind of society."[380] Citizens groups, too, embrace participation: "Ordinary citizens using the tools of dignity, self-respect, common sense and perseverance can influence solutions to important problems in our society."[381] Choice is an element implied or made explicit in many authors' descriptions of participation,[382 383 384 385 386] as is the view that participation is essentially a political phenomenon concerned with power.[387 388 389 390]

Several models of participation have gained popular acceptance, notably Arnstein's early "Ladder of Participation"[391] which describes eight incremental steps of citizen control and involvement in political affairs, from non-participation through degrees of tokenism to degrees of citizen power. The model by Rifkin et al [392] examines participation along a continuum from wide participation to narrow in five areas: needs assessment, leadership, organization, resource mobilization, and management. The authors acknowledge, however, the inability of their model to include an important area--equity.

Goulet[393] identifies three constructive functions of participation in health and development:

- ensuring dignified treatment of people beyond their utilitarian role;
- serving to mobilize, organize, and promote action by people to resolve their own problems; and
- opening up channels through which communities can gain access to larger spheres of decision-making.

Participation is most successful, he claims, when based on moral incentives of a community's success and confidence at the local level, matched with material incentives which enable progress and further achievement.

In recent years, some authors[394 395 396 397] have voiced criticism about what they see as the co-optation of the concepts of participation and

empowerment by the health sector. Some government health promotion initiatives are seen as having shifted the meaning of these concepts. From being key elements of organic, community-based movements in which people become empowered and have a decisive role in decisions which affect them, participation .has become synonymous with behaviour change and compliance, and empowerment as something bestowed on people by involvement in government-run programs.[398] This study distances itself from these co-opted meanings and views the concepts as they were originally intended.

One way to reflect on participation in our project and research is by using Goulet's typology:[399]

• *Is participation a goal or a means?* Freire argues for a dual means-end focus, which is what we attempted in our work. Active dialogue was fostered throughout the process for its value in increasing self-worth and empowerment, yet we recognized that participation would also lead to efficient, appropriate achievement of goals.

• *What is the scope of participation?* The scope of the arena in which participation operates may range from a family unit to a national program. Our scope was the project and research and its immediate environment, which was manageable but, at the same time, limited in its influence. Enduring, wider effects are occurring through the grandmothers' ongoing participation in activities related to the project which are still funded and have policy-making functions, such as the district health Aboriginal subcommittee.

• *Who is its originating agent?* The originating agent of our initiative was the sponsoring community clinic, a third party promoting a connection between the federal government funder and a community of people. Participation that is "state-promoted" usually focuses on people's input and production, whereas that "spontaneously generated" from the grassroots often occurs in response to a crisis but includes power-sharing--seeking a greater "share of the pie." A third party may

239

bridge the two originating agents, as in our case, fostering both capacity-building in the community group and flexible support from the funder.

- *When is participation introduced?* The point at which participation was introduced in our work was following establishment of project goals, but prior to most other project and research activities. Preferably, the goals would have been allowed to evolve according to the interests, wishes, and capacities of the grandmothers as they formed a community, shifting the focus of the staff and me more directly to their personal and collective growth rather than achievement of pre-set goals; otherwise, participation was early and sincere.

From these criteria, Goulet characterizes participation which contributes to authentic human development as that which is both a means and an end, originates from non-elites, and is initiated early in a project's development.

Maximum participation in research by members of a community can be argued on many fronts. Fals-Borda and Freire write of the relationship between ideas and power, and the role of participation in giving a voice to those who dwell in the "culture of silence." Others[400] [401] [402] promote participation because of the transfer of understanding and skills among members of communities and between communities who are engaged in PAR. Tandon[403] and Barndt[404] contend that maximum participation in research creates the conditions for collective social action. Each of these situations occurred in our work. The traditional voice of the Aboriginal grandmothers was strong, respected, and influential, and the prominence, opportunity, and platform that the project and research afforded the relocated, contemporary grandmothers at least partially restored that voice. The competence, capacity, and value that the grandmothers exhibited and further developed did spread throughout their group and, as well, influenced others beyond them, directly affecting other community groups to adopt a PAR methodology in their research endeavors. The emphasis given in the project and research to the grandmothers' ability and role to strive to improve conditions for

their grandchildren mobilized their resources for social action from time to time, as their health permitted.

Participation by the grandmothers in project and research activities gave them control of aspects of their lives connected with this initiative. As apparent by the description and analysis of their involvements, in section 3.1 and 4.1, and the presentation of findings, in section 4.3, both their actual and perceived control increased. This sense of control was not characteristic of many other aspects of their lives. The enjoyment and satisfaction that the grandmothers experienced from their participation in our activities was influenced by the unique nature and extent of control they held over the project and research.

An additional way to look at participation in our work is according to five evaluation criteria set out by the Pan American Health Organization of the World Health Organization (1994):

• *extension--who participates, who does not, and why?* The reach of the project extended, through ongoing inquiries, to at least minimum contact with all grandmothers known to be in the city. There was a core of grandmothers who were most active and regular but only about half of those were with the project most of the way through, so much participation was inconsistent. Of the ones who did not stay involved, some found there was too much "business" done, one found too much personal healing work which discomforted her, still others were constrained by ill health or caretaking responsibilities, and a few who spoke little or no English found language a deterrent even with translation. As reported in the "Findings" (section 4.3.6), grandmothers entered the project at different levels of participation, some being quiet for a long time before developing comfort, and others more readily speaking up and being active. Each progressed at a different pace, as well, based on many factors, including her past socialization, basic personality, level of biculturalism, facility with language, and state of physical health. This progression was not entirely linear, as it was influenced by the vicissitudes of these women's lives.

- *intensity--what do people participate in?* Participation was encouraged at most points and levels, excluding project goals, budget, basic job descriptions, and supervision of staff. The grandmothers had the skills to develop project goals (which they were not asked to do) following development of a group identity, cohesiveness, and clarity of purpose, and determine program activities which they did do to a large extent. The central activity in which they participated was the Tuesday morning get-together, and from that we planned others. They were little interested in the administrative side of the work, and were reluctant participants or nonattenders in some activities offered to them. Many had never taken part in committees or organizations and gradually learned these skills if they continued attending, which some did. Generally, the greatest participation was achieved for cultural and social events, or when the staff emphasized an event as very important, such as the meeting with the provincial minister of social services.

- *integrity--how is participation conducted?* To a large extent, the grandmothers relied on the facilitation of the staff to organize and conduct activities, and did not readily or spontaneously move into roles of management, mediation, or leadership. Rarely did they set their priorities or make their decisions explicitly, and the staff or I had to coax their direction and choices from them so as to understand their wishes. Their approach often was to avoid contentious discussion, issues, and conflict, and leave a matter until consensus built naturally and a decision emerged from the group. The occasional time someone broke that pattern with open criticism, a cutting remark, or personal anger vented into the group, the tone of the group fell and in subsequent weeks, participation from some others fell off.

- *sustainability--what about capacity of participants and continuity of processes?* The capacity of certain grandmothers to advocate for themselves and issues important to them clearly increased. The processes of personal healing, group activity, social action, and developing a public profile have continued after the project, via different avenues. Yet the loss of project funding has lessened the potential for greater impact.

242

•   *impact on health goals--what has been achieved?* The outcomes
of the grandmothers' participation in the project and research are
indicative of growth, development, and empowerment which all signal
improved health and well-being.   Collectively, therefore, participation
did have a positive impact on health.   Individually, the impact was
variable but with each participant experiencing some healthful benefit
from her engagement.   The progression of participation and the
emerging outcomes are parallel to and indistinguishable from the
empowerment process, which allows this study to claim empowerment of
the grandmothers as an overall benefit.

Another area to look at regarding participation is the transformed
researcher-subject relationship which serves as a microcosm of
empowerment.   The intent and approach of the relationship established
between the grandmothers and me fostered their autonomy, self-worth,
and self-determination in thought and decisions from the minor to the
more significant issues.   By means of *vivencias*, the "asymmetrical . . .
relationship of submission, dependence, exploitation and oppression"[405]
was intentionally broken.   Rather than the typical researcher-
researched relationship in which the subjects are "mined" for their data,
equity was established which was then carried over to other parts of the
grandmothers' lives, including the family, health and social institutions,
and community committees and initiatives.   The essence of true
participation in all these relationships was mutual respect and value.

Action

Action research was popularized by Kurt Lewin in the 1940s when he
argued for a cyclical nature of research and programming/action--
studying things through changing them and seeing the effect--then
continuing with further cycles of research and action.[406] For
proponents of PAR, action is fundamental so that injustices are
challenged as issues are investigated and people become aware of the
oppression in their lives.   Action may serve as a way to move from

individually-focused growth to a social analysis and involvement, shifting from the private domain to the public.

In our work, we emphasized action throughout, both because of the grandmothers' disdain for research not applied to practice and because of the philosophy of PAR in which the staff and I believed. The values we held of respect, love, caring, support, and compassion, and the phenomena of participation and empowerment demanded that action be taken as problems, questions, and challenges surfaced and were shared. In the cyclical progression of PAR, action taken becomes itself an influence affecting further favourable outcomes with the grandmothers. In other ways, action was a result of growth the grandmothers were experiencing; as they developed awareness, confidence, and solidarity amongst themselves, they were increasingly interested in and capable of taking action. The "form of action people adopt is to a large extent a function of how they perceive themselves in the world."[407]

This is consistent with Shields' study,[408] which found a major element of empowerment in women's experiences was the development of an internal sense of self, which then formed the base for a second element-- the ability to take action and participate in life. In contrast to the picture of action in this inquiry which focussed on group maintenance activities and community connections, Shields categorized more individual, personal gains as action, but there is much similarity and overlap in several subthemes. The women in her study described actions as having a voice to communicate their inner self, taking a risk to expose the true self, the development of skills (communication, cognitive, self-care, physical, and community involvement), and the emergence of critical thinking.

Emphasizing action in the grandmothers' project and research put the focus on addressing risk situations, rather than on personal risk factors or behaviours which end with a "blame the victim" and behaviour change approach to problem resolution. Maintaining the action and situational emphasis was consistent with our philosophy that social and

political change is necessary for ending marginalized people's oppression.

In a recent study on significant elements of community participation in PAR, one respondent spoke of the relevance and congruency of their action-oriented research:

> Here was something that was going to make a difference. It was with the University, it was research, but it was actually making a change right away. And that was magic . . . It was so hands on, it was immediate, it was important to our lives.[409]

Silence

Overall, the findings of the study are persuasive evidence of growth in the grandmothers. Yet the findings are heavily determined by what the grandmothers said about the project and therefore what data was accessible to me. What they did not say during that time period is noteworthy, as well. Almost never in the group was there discussion on tension or conflict, although it existed, and nothing was mentioned in the interviews during the project. Yet six months after the closure of the project when the former coordinator interviewed many of the grandmothers about their perspectives on Aboriginal ways to handle conflict, they were very forthcoming and candid about their experience in the project (described in section 4.1).

An insightful article by Gerrard and Javed[410] raises many questions about racialized women and silence and provides a framework for reflecting on what was not said in our work and why. Like all of us, older Aboriginal women are socially constructed--they by traditional values and ways of life, but also by racism, sexism, classism, and ageism. They learned to be silent in their lives to cope with many hardships, and learned to be grateful for what resources they were offered. Gerrard, in remarks to Javed, uses the metaphor of an object and a mirror, the one being three dimensional and the other two. Reality is more than a two-sided mirrored reflection of the object. It is composed of the object, the reflection, and the space between them, which is analogous to the

245

grandmothers' realities of what was visible, what they said, and the invisible unexpressed connection between the two.

During the post-project interviews, when asked about conflict, the common response of the grandmothers was that it is best to avoid or ignore it. Also, with the coordinator and outreach worker, when tension and conflict were discussed both during and after the project, the response was the same--the way to deal with it was to work around it. The director and I bowed to that opinion since we were crossing cultural boundaries, but we also chose to accept that position and allow the idealized picture of the project to prevail. We did not even name what was going on, "thus ignoring cultural practices"[411] and thereby contributing to the silence. Racialized women's silence must not end in self-blame but must be viewed in the context of racial, gender, and class oppression which teaches silence. Ignoring and avoiding tension resulted in the project continuing with apparent harmony, but with attrition from grandmothers who found it uncomfortable and disagreeable. Ignoring and avoiding also resulted in a lost opportunity for the project to further deal with real problems of relocated, socially disrupted people who must relearn functional patterns of living and working together. Moreover, an opportunity was lost to learn skills of group dynamics which would be useful to the grandmothers in many other situations. Tension and conflict needed to be named as normal and inevitable, and rules agreed upon for handling these occasions which would work for resolution, not suppression.

4.4.3 Empowerment and a Model in Health Promotion Practice

The sum of the outcomes of this study describes empowerment at many levels, expressed in different ways. Lord and Hutchison[412] conducted a study with men and women who had experienced extensive powerlessness in their lives in order to understand their experiences toward increased control. They found that empowerment is a process and a constant struggle; few people "become empowered." In response to some catalyst, participants in their study identified two vital changes in the first stage of their own empowerment: becoming aware of their own strengths and

capabilities, and developing new directions and making change for themselves. These are consistent with the outcomes of project and research participation for the grandmothers. Furthermore, several of the critical elements that those participants identified as providing impetus for change were seen in our work, too:

- being in a life transition (for the grandmothers, suffering ill health, moving to the city, aging);
- acting on anger or frustration (family crises and burdens, and institutional barriers);
- having and responding to new information (about personal strengths, self-care, illness, resources);
- support from people; practical support; moral support (from or via each other, project staff and me, community resources);
- access to valued resources (those that were personalized, responsive, interactive, and fostering self-reliance and client control);
- participation (a cornerstone of our work).

The respondents in Kieffer's study[413] of emerging citizen leaders in grassroots organizations experienced empowerment as a long-term process of adult learning and development. Similarly, our grandmothers felt more empowered over time, seeing themselves as assertive and contributing members of society.

<u>A model of empowerment in health promotion practice</u> The outcomes of our study differ from but are compatible with Labonte's empowerment holosphere which depicts five distinct yet overlapping spheres of health promotion practice (see Figure 4). In his monograph,[414] he clearly states that the holosphere is for professionals and their organizations to examine their practice and not for the people with whom they work. As such, the holosphere is used to examine how the staff and I guided the project. In addition, however, because of the grandmothers' central role in most project activities and decisions, liberty is taken with the model and it is used, also, to look at the grandmothers' actions and attitudes. Since the spheres are a representation of actual health promotion

247

programming, surely they can be used to analyze a community's participation in that programming. The value of examining our work in relation to this model is to identify distinct yet interdependent areas of focus of our project programming and recognize anew that each is important, to use another "lens" to look at the outcomes of the grandmothers' participation, and to acknowledge the compatibility of PAR with this process and the role it can play in fostering empowerment and community development.

From the practitioners' perspective, there are many interpretations of the model's spheres. They represent foci of programming for health promotion agencies; each is distinct yet interrelated and symbiotic; each is legitimate for a community health agency to be involved in; and each has distinct aims and activities. The holosphere is drawn with overlapping circles in an overall circular design that depicts the interaction among the spheres. Nonetheless, there is a natural, incremental, developmental direction and flow, also, from the personal care through to the political action which represents ascending levels of activity. The holosphere is consistent with the steps of community development[415][416] and PAR.[417][418]

The Empowerment Holosphere

Figure 4   The Empowerment Holosphere   Labonte, 1993

From the holosphere in relation to our project, it is clear that the staff and I truncated the time frame we spent in the spheres of personal care and small group development, anxious to get into the "more important" work of social action and change.   Our very limited funding period, initially 18 months with a further 18 months granted later, contributed to our sense of urgency in achieving our goals; these goals we later recognized as too ambitious.   Labonte argues that in the first year or two of a project it is reasonable to aim for group dynamics outcomes such as stronger group identity, role differentiation within a group, clarity over norms, and so on.   This is particularly relevant for our project since the group was being newly created through our programming.   Further, Labonte makes the point that "we need groups that nurture the soul, and groups that challenge the *status quo*," . . . that these two levels--the personal or interpersonal and the socio-political--are not contradictory but complementary."[419]   We hoped our project would be both, and it was.

In our regular staff meetings, we periodically harnessed our expectations and reminded ourselves of the literature on community development which emphasizes the importance of and time needed for group building. Yet, interest from the community, expected outcomes of the project, our

own urgency for the grandmothers' to be heard, all combined to accelerate the pace with which we guided the project. It was the grandmothers who slowed the project and allowed it to proceed only at a pace with which they felt comfortable.

Each of the spheres of the model describes a number of involvements undertaken for project and research programming by the staff and me, and also relates to the categories of study outcomes, which is where liberty is taken with the model.

Personal care: This sphere parallels the *cleansing and healing*, and *connecting to self* study outcomes, and in the holosphere is the area of direct services where many front-line workers meet their clients. In our project, many of the grandmothers had personal care needs and often the staff and I were the most accessible people to work with them on meeting these needs. Contact at the personal care level served two principal functions: actual needs that the grandmothers had were addressed; and the interaction provided an opportunity to build a relationship. It was in these personal contacts that I felt the grandmothers' acceptance and trust of me grow, bridging the obvious distances between us. After making a home visit and doing some problem-solving with a grandmother, there would be a discernible difference in our relationship at our next group get-together. Thereafter, I felt that the grandmother saw me as a person who cared for her, affirmed her situation, and gave of self to assist her in whatever way was needed. In this sphere, Labonte calls these "respectful services." These personal care contacts also allowed me to see each grandmother as unique, and know and appreciate her personal home context. Often, a relational dialectic developed: the more the staff and I worked with the grandmothers on their specific problems, the more they took part in the project and contributed to the group.

Small group development: This sphere is related to the study category *connecting within the group*, and the term refers to support or self-help groups that focus primarily on the social, emotional, and behavioural needs of their members.

The grandmothers liked the time they spent together, visiting, sharing what was going on in their lives, cracking risque jokes and laughing uproariously, and enjoying food. The pivotal programming activity was the Tuesday morning get-together, and this was viewed by the staff and me as the principal group and community-building strategy. Still, this small group development sphere deserved and demanded more attention than the staff and I gave it. Typically, we used the weekly group as an opportunity for other purposes: to hold a healing circle or educational; to cover organizational business; to host a speaker who requested time to talk to the grandmothers about a new initiative or a community concern; to make progress on the health assessment; to make announcements and organize grandmothers' involvements in community activities. Periodically, the staff and I reminded ourselves that the building and nurturing of the group itself was a specific programming objective with its own worth. Only then did we plan specific activities to accomplish greater cohesion, better dynamics, and continuing development.

It was tempting, and may have been satisfactory for many grandmothers, not to push beyond these first two levels. Yet, for several reasons we did so: agencies and groups in the community welcomed the formation of the group and invited them to participate in initiatives; the staff and I saw the group as a community resource and capable of playing a valuable role in community development, thus we urged them into socio-political realms; and some grandmothers articulated a desire and responsibility for regaining their traditional role as cultural teachers, guiding the young in their urban environment, and publicly taking a stand on issues about which they felt strongly.

Community organization: This sphere and the next two are encompassed in the study outcome category, *external exposure and engagement.* Community organization refers to the process of mobilizing people and dealing with issues beyond their own immediate concerns.

From the perspective of funders and practitioners, the grandmothers qualified as a priority group for support, given their low position in the hierarchy of political and economic power. For the grandmothers, there

251

were community issues beyond their own immediate concerns that caught their interest and caused them to organize. Principally, these issues focused on the health and well-being of children and families, which included: children in prostitution, the construction of a long-term care facility's Aboriginal unit, the development of a traditional parenting skills curriculum, an outreach diabetic education program, and nuclear waste storage.

At times, there was resistance, passive and/or active, from the grandmothers when the staff and I tried to draw them into activities to which they did not relate well, or into involvements and responsibilities when they were feeling burdened and overwhelmed in their own lives, or when they simply objected to being busy at the expense of enjoying each other, drinking tea, and sharing laughs. When this happened, we were obviously not attending to the first axiom of community development, which is to start where the community group is at--their priorities, their understanding, and their way of working.

Yet we would have passed Labonte's "acid test" of citizen participation, rewritten from Arnstein's[420] definition of complete citizen control definition in her classic "ladder of citizen participation." Labonte maintained that the "acid test should be the equality and empathy--the intentional effort to create equity--in the relationships between citizens, community groups, professionals and service organizations."[421] That we achieved in all community organizing that the grandmothers, staff, and I worked in together.

Related to the study outcomes category, *acquiring knowledge and skills,* Labonte cautions against idealizing "the community" as embodying "the capacities, problem-solving potential and human caring that are often missing from our bureaucratic, political, and intergroup organizational styles."[422] In fact, the staff and I were continually reworking our expectations of the grandmothers in the project, reminding ourselves that most of them had troubled lives--culturally, economically, and socially. Furthermore, they did not have some of the capacity, knowledge,

252

and skills required for community development work, and these would need to be acquired.

Coalition-building and advocacy: Coalitions are groups of groups with a shared goal and an awareness of the strength in unity. Advocacy refers to taking a position and action on an issue with the intent of influencing public policy. Advocacy often involves coalitions and coalitions usually advocate. In the second half of our project, the grandmothers, staff, and I took an active role in coalitions. Through these, we advocated for improvement in socio-health issues, "with" not "for" the grandmothers.

The grandmothers found participation in the coalitions interesting and stimulating, and for some it was novel to be involved in a multi-agency activity. Being in a coalition expanded their understanding of issues as they listened to discussion from a number of different individuals and perspectives. Yet for some grandmothers, consistent attendance was difficult due to other demands. For those who did continue, the coalitions valued their participation.

The many partners in a coalition also gave strength to the grandmothers for dealing with issues that they alone would not have been able to tackle, drawing in a variety of skills and resources. This expanded group contributed to both a perceived and real empowerment for the grandmothers. Without the support of a coalition, many groups such as ours would be unable to participate in more ambitious, higher level activity.

Political action Political action refers to intense, focused action through coalition advocacy aimed at social change. In our case, though, the greatest thrust into the political arena was from outside a coalition, regarding proposed nuclear waste storage, as described in section 3.1 and 4.3. It was the issue that struck the strongest, most common, and responsive cord among the grandmothers. Because enabling the grandmothers to act on their concerns took a lot of staff support, when the project funding ceased, the grandmothers' response did as well; yet

253

their concern continued. Certainly, if further action were to occur, it would be more effective as part of a coalition.

Of the few grandmothers who had been active before our project in Aboriginal political issues, one had personal experience with the tribal council involved with the uranium waste storage proposal. The staff and I suggested she speak directly to the council as she would be influential. She declined, even though she felt strongly about the issue. She explained that a number of years ago, she had been outspoken on a different contentious issue with another group and had suffered repercussions because of her stand. It was clear from the way she spoke that the experience had affected her deeply. As an individual, she was not willing to put herself at risk again, but as part of the group she would speak up, attend discussions, and write to the premier. She did, however, agree to be our spokesperson for a radio interview requested by the national broadcasting corporation in response to our letter to the premier. In the interview, she spoke with clarity and conviction.

As in community organizing, there was tension in the sphere of political action between what the grandmothers and staff saw as their cultural role and responsibility and what the grandmothers enjoyed doing on a day to day basis--planning feasts, visiting, enjoying each other. We always had to strike a balance among involvement in the different levels of activity.

Both the way the staff and I guided the project, and the outcomes from the grandmothers' participation in the project and research resonate well with the five overlapping spheres of the empowerment holosphere, showing varying degrees of individual, group, and community activity.

4.4.4 Trustworthiness

As mentioned before, this inquiry on effects of participation and the PAR experience was an interpretive case study, using qualitative methods and data. Its primary purpose was *understanding* the role of PAR in health promotion, rather than discovering a law or testing a hypothesis as in an

experimental positivist study. As such, the criteria for trusting that the study was rigourous can be based on examining its components: that the interviews were validly constructed; that the data were collected, verified, and analyzed appropriately; that the findings and interpretation of the study resonated with the data.[423] [424] If the methods employed and other components in the study can be trusted, then the reported and interpreted findings are believable.

The interviews were validly constructed and the data collected, verified, and analyzed appropriately, as described in sections 3.2.2 - 3.2.4. The findings do resonate well with the data, and with general observations and feedback from others involved with the grandmothers which were not used as data *per se*.

According to Lather's[425] four techniques to examine validity of "openly ideological" research, our work scores well:

1)   <u>triangulation</u> The research on participation drew on data from different subjects, used data collected over an extended study period, used multiple data collection methods, member checks, and employed various theoretical constructs, all of which triangulated and verified the data. An additional element used was peer debriefing[426] with my reflections committee. Eight members, with expertise in areas related to this research, reviewed all the preliminary findings on the grandmothers' participation and met with me individually or in groups, providing thorough and constructive feedback. This very useful technique verified my analysis and interpretation, and offered further insights which I incorporated into this thesis.

2)   <u>construct validity</u> Even though participation and empowerment were central principles of the context in which the research was embedded, this was a nonparticipatory inquiry of a participatory process. Greater construct validity could have been achieved if the grandmothers had had a more active role in choosing the criteria and methods to examine the effects of their participation in the project and research. They did endorse the interviews and verify the findings but, considering

the limited accessibility I had to them and the many requests I and others had for their time and attention, I did not attempt to involve them further. My judgement was that further collaboration would have been more burdensome than empowering.

3)   face validity   This technique permeated our research.   The analyzed data from the health assessment and the effects of participation on the grandmothers were turned back to the grandmothers and staff in open and continuous dialogue.   There was ongoing opportunity to judge whether the analysis appeared to make sense.   The findings of this research do appear reasonable and logical.

4)   catalytic validity   My research did not include critical analysis of findings or context.   It did, however, serve to "mirror" to the grandmothers the changes in themselves and the others, providing an opportunity for each of those interviewed to reflect on outcomes of their participation in the project and health assessment research.   When their collective voices were composed and analyzed, they were clearly impressed with the wisdom and scope of their opinions and reflections, all of which was empowering.

Regarding generalizability, the findings of this study are specific to the grandmothers in this particular project and research as described.   Yet from the thick description of this case, others may learn from our outcomes and lessons which might be useful for related inquiry.

Examining the study against these validity criteria, the findings as reported and interpreted can be trusted and believed.

4.4.5   Subjects

The grandmothers were the central subjects in this study, while the advisory committee, staff, research associates, and other community members had minor roles. A composite picture of the grandmothers is an older woman, of Aboriginal ancestry, low income provided by government sources, residential elementary school education, migrant to

the city from a rural or remote area, bore five or more children and has many grandchildren, living with family members, practising few traditions, and experiencing dissonance. Each was familiarly known as an "auntie" or *kohkom*. It bears repeating that none of the project grandmothers was a traditional elder and few had had much experience articulating or representing themselves or their culture to others.

The most prominent characteristics the grandmothers identified with were being Aboriginal and having grandchildren. When we critically reflected on their lives and the issues they felt most strongly about, these two variables were the ones they most readily and emotionally discussed. Our conversations did not take the form of explicit or deep analyses through problem-posing dialogue but rather through more oblique references during personal disclosures and story-telling. The difficult, challenging, and painful experiences they each endured throughout life could often be traced back to racial discrimination at an individual, institutional, or societal level. Also, they saw their low socioeconomic status as determined principally by their Aboriginal identity rather than by gender, health, age, employment, or education.

Antonovsky,[427] in a study of women on traditionalism and adaptation, found that the crucial variable in successful adaptation was not the content of their culture and social structure but its relative stability. The grandmothers had experienced great instability in their lives because of the breakdown of their traditional socio-cultural environment which affected their immediate families and their communities, resulting in distress, role and identity confusion, and maladaptation.

The grandmothers' advanced age was most evident as a limitation in their physical health which greatly determined the nature and extent of their participation in the project and research. At the same time, their age was an asset in many ways: their mature perspective on issues, their personal warmth and caring for one another, their tolerance and understanding from many life experiences, their relative retirement despite ongoing caregiving responsibilities, and the implicit respect given them by the community at large.

While not identifying with the feminist movement or attributing their reality much to gender issues, the grandmothers clearly related as women and their relationships, attitudes, beliefs, and behaviours were strongly feminine. My inclusion in their circle was enhanced by occasions on which we shared stories and experiences common to women, mothers, caregivers, friends, and helpers. Despite our differences, we shared those traits and experiences.

A theory on a sense of coherence (SOC) and its relation to health was constructed by Antonovsky,[428] and is useful to explicate some beliefs and behaviour of the grandmothers. A sense of coherence is defined as "the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected,"[429] A strong sense of coherence, Antonovsky posits, is salutogenic, or health promoting; a weak sense of coherence is detrimental to health, and is related to learned helplessness[430] and powerlessness. Seligman stresses that what drives this sense of helplessness is not the experience of failure *per se* but the belief that what happens in one's life is beyond one's control; stated differently, that one's behaviour does not determine outcomes. This kind of thinking is especially prevalent during societal transition and breakdown, such as in colonization and "detribalization."[431] In contrast to this, characteristic of higher social class is the expectation that one's decisions and actions are of consequence, and will determine outcomes.[432] A strong sense of coherence is related to this research's central influence--participation. The grandmothers' participation in both personal and collective activities did indeed influence and effect outcomes set by the project to be attained.

Yet many of the grandmothers' life experiences led to a weak sense of coherence. To a large extent, their lives were not predictable, their actions did not produce the outcomes they should be able to expect, their world was full of social disorganization, few options were open to them, strong social forces constrained their ability to maintain effective social

258

units, many relationships were dysfunctional, frustration and punishment were common, and they held marginal status in society. Overall, they were exposed to many stressors with few supportive, protective factors. Antonovsky maintains that change is possible, the important variable being an increasing opportunity for choice, especially that which develops the personal capacity to deal with threats to one's health. In a small way, the project and research provided that to the grandmothers--opportunities for choice and development in personal and collective growth, and experiences in which their actions led to desired outcomes. Presumably, that possibility of change diminishes with age, yet the findings of this study are evidence of change.

4.4.6   Limitations

This is a qualitative case study. Accordingly, the relationship between PAR and health promotion is examined in one case only, with one population, one methodology, and selected methods only. No comparative study is being attempted, and no generalizability is warranted other than as discussed earlier.

Notwithstanding the benefits of case studies, there are potential disadvantages as mentioned earlier in section 3.2.1--being prone to exaggeration or oversimplification and the dependency on the writer's interpretation.[433]   To weigh these disadvantages in this study, the reader is directed to section 3.2 on methodology, section 4.4.4 on trustworthiness, and the thick description presented by this document.

This concludes the discussion of the primary objective regarding effects of participation. The next and final chapter brings the thesis to a close with a summary, implications of the work, and remaining and related questions and areas for further research.

Endnotes:

*   One was a daughter by her first marriage, and the other was a distant cousin.

259

†   Absorption capacity is a term used in international aid and development which describes a developing country's ability to use resources offered to it, largely determined by the extent and functioning of its infrastructure; the term is applicable to the grandmothers' ability to participate in the research and other project activities.

**   Elders are individuals who have a special role in spiritual matters, teachings, and other traditions. None of our grandmothers, although they were middle-aged or older, considered themselves elders.

††   "*Kohkom*" is the popular version of the Cree word "grandmother" although, correctly, *kohkom* specifically means "your grandmother," and is not a general term.

5. Summary, Implications, Research Questions

To recap, this inquiry was a case study of the utility and appropriateness of PAR as both a research methodology and intervention for health promotion. Two objectives guided the work: to examine the effects of participation in the project and research, and to describe and reflect on the experience of using PAR within a health promotion context. This document has presented and analyzed the experience of employing PAR to promote the grandmothers' health through its use in conducting their health assessment. Furthermore, the changes in the grandmothers from their participation were reported and discussed.

This last chapter summarizes and briefly discusses the major findings related to the two objectives, considers the implications of our study for other related PAR and health promotion initiatives, and closes with some research questions that stem from our work and deserve further attention.

5.1 The PAR Experience

The next four sections are summaries of material already presented on the project and participatory health assessment and thus are repetitious. The fatigued reader could jump to section 5.1.5 which offers more synthesis.

5.1.1 Overview

Following the definition of PAR given in the Introduction, PAR in this study was the methodology used for a health assessment inquiry by the grandmothers as researchers themselves, exploring questions in their daily lives, recognizing their own resources, and producing knowledge

and taking action to overcome inequities, in solidarity with external supporters.

PAR demands rethinking the question: Research for whose benefit? The grandmothers held the perception of research, common to Aboriginal and other marginalized peoples, as something done to them, for the benefit of outsiders, and from which they receive no gain. In contrast, our PAR experience embodied the values of equity, respect, capacity, holism, commitment, and connection. Our research reduced the positivist separation between researcher and subject, with all members of our research team working as equals and partners, each bringing to the experience unique contributions, and gaining from it special rewards. Our purpose, as in all research, was to create new knowledge, yet not only as an end in itself but as a means for the grandmothers to empower themselves.

The positivist paradigm also insists on separation between research and action, which results in researchers being spectators, scrutinizing phenomena, all the while abdicating any responsibility to act on what is learned. PAR challenges this informed passivity. In our research, reflection, inquiry, and action were integrated and cyclical, with the research team recognizing the hurdles affecting the grandmothers and throwing our combined resources to address them to enable the grandmothers to further their own well-being.

From their history of oppression and current relocation, the grandmothers experienced a culture of silence, invisibility, and isolation. Accordingly, the emphasis of the project and our research shifted to personal and group development in response to this reality. Socio-political analysis and change occurred but depended upon the well-being and capacity achieved by the grandmothers.

Despite the grandmothers' unfamiliarity with theoretical critical analysis and their distaste for what they called "Indian politics," they reflected on their own lives and established their presence and voice in the community, demonstrating courage and conviction on issues important to

262

them. Now, after the project and research are formally finished, continued growth and activism are of interest to them but ongoing support is not available (implications of funding cessation were discussed in earlier sections).

5.1.2 The Grandmothers

Aboriginal people in Canada have a long history of cultural invasion which has attempted assimilation but failed, and of research which has quantified and described their reality but has done little to improve it. The federal government's 1969 assimilationist White Paper on Indian Policy triggered a trend, however, to establish participatory research as an Aboriginal strategy for political strength, setting up traditional land claims, and leading to self-government. Yet the PAR methodology is little used in grassroots Aboriginal social, health, and cultural research in this part of the country. In our city, older Aboriginal women were seen as a group with many unmet health needs. Since assessing and addressing these needs may not have been amenable to a more conventional research approach, the trial of an alternative model, such as PAR,was warranted.

The grandmothers of the health promotion project and participatory health assessment research were representative of their history and culture. Their principal identification was of being Aboriginal; class, gender, and age were secondary self-identifiers. In their home communities, they had grown up, married, and raised their families, meeting the threats to their communities' social, economic, and cultural integrity as well as they could. Their innate and acquired strengths were many, yet the traumas in their lives were numerous and daunting and often resulted in oppression and silence. Typically, in their later years, they moved to the city to be with their children and grandchildren and to be closer to medical services, yet this urban environment was alien to most. Many lacked coping skills for this setting, had a weak support system, and became isolated. Furthermore, although the grandmothers had traits in common, they were not a homogeneous group. Their differences included being First Nations or Metis, growing up in the

263

remote north or the more urbanized south, being more comfortable in English or their native language, having varying familiarity with Aboriginal traditions, having a wide range of formal education and employment, and experiencing varying degrees of socialization beyond their immediate family. All these factors played a role in the nature and extent of their isolation and their response to our work together.

The grandmothers were the principal participants in the health assessment and the central subjects of the inquiry on the effects of participation. In the beginning, they rarely spoke up for themselves. They were shy and gentle, yet enjoyed a good laugh. Their quiet demeanors, however, masked characters of strength developed from years of confronting adversity. Some were able to join the project, showing spirit, humour, and enough health and well-being to be involved. They found therapeutic value in coming together and, in the absence of traditional elders, they gained guidance and support from each other. They became more empowered, forming a new community, healing and growing, supporting one another, and mediating between themselves and the world beyond the group to both extend their voices and draw in other resources. Their resilience strengthened and grew.

5.1.3 The Project and Research

The project and participatory health assessment provided these grandmothers with an opportunity and encouragement to form a community in which they could take part, connect, and belong.

> *It doesn't take much*
> *a little attention and caring,*
> *kind words, warm clasp.*

Through this community they were able to better develop resonance and well-being in this urban setting--learning other coping skills, establishing new social support systems, and reclaiming their traditional role as sources of wisdom, guidance, and love. Within the structure of the project and research, they embraced activities for healing and personal development, recognizing their own strengths and value, and growing in

264

self-esteem and self-confidence. They formed a family of compassionate sisters and aunties who cared for one another and for others. They spoke up and out on issues they felt strongly about, advocating for themselves and the larger Aboriginal community. Yet without ongoing project support now, the grandmothers maintain reduced contact with each other, in select initiatives only, and have reverted to some isolation and silence.

5.1.4   The Research Process

Each PAR experience is unique but there are common theoretical elements, qualities and stages, characteristics and other elements, and assumptions and challenges. Despite certain areas of divergence, the PAR we conducted was congruent with much of the description in the literature.

Our work fell into four stages, with negotiation and dialogue being done early among the advisory committee, staff and me, but continuing well into the project as the grandmothers took over from the committee, new grandmothers joined in, and the stigma of research blocked the staff's collaboration at first and the grandmothers' later on. Orientation was a protracted phase as well. The advisory committee, grandmothers, staff, and I took many months to begin developing comfort and ease with one another. As new activities emerged, new grandmothers or the research associates became involved, and group roles, functions, and dynamics changed, we needed continued orientation. The joint research began with the the advisory committee planning workshop in March of 1993 and continued through to the publication of the health assessment report in June 1995, and on to the dissemination of results at the Sharing Our Values workshop in October 1996. Joint action was carried out in response to interests, concerns, and problems that arose throughout the project and research, and beyond; some actions were short-term yet others continue at the time of this writing through the grandmothers' participation in other ongoing initiatives. Joining the research and action cycles were phases of reflection, the aspect of PAR in which participants thoughtfully consider what the inquiry is finding out, what

action is appropriate, and what the action is achieving, in order to feed back into the further loops of reflection-inquiry-reflection-action.

To conduct a health assessment using conventional research, external researchers identify and interpret a community's needs and problems (and ideally, resources) using various sources of data and methods of analysis. In PAR, community members determine the nature and extent of the assessment and contribute, analyze, and interpret much of the data, as well as act on them.

Our research involved various players:

- The advisory committee, who defined the type and scope of the assessment.

- The grandmothers--the central participants, who shifted the focus from needs to strengths; provided most of the data; endorsed the technical work of the research associates, staff, and me in designing the interview guides, consent forms, work plan, and contracts of the associates; verified the data through member checks as a group; did secondary analysis and verified interpretation of the data through their scrutiny and revision of repeated drafts of the assessment report; and took action on some of the findings and other issues arising.

- The staff and I, who guided, mediated, facilitated, and advocated for the assessment process, doing initial negotiation, orientation, and development with the advisory committee, then conducting the technical aspects of data collection, analysis, interpretation, reporting, and dissemination in collaboration with the grandmothers.

5.1.5 Determinants of Success

Many factors, or determinants, contributed to the success of our participatory health assessment.

- The health assessment research became a program of the project, embedded, integrated, congruent, and balanced with other activities, and evolved slowly and incrementally the way the rest of the project did; it was not seen as an external, separate initiative. The agenda for proceeding with the assessment was constantly adapted to whatever was happening with other project activities and the grandmothers themselves. Timelines became elastic. In the words of our coordinator, the health assessment was "flexible . . . it wasn't too heavy."

- Even though the advisory committee and grandmothers did not decide themselves to conduct the health assessment, all other decisions and activities of the health assessment were under their control and/or involved their active participation or endorsement.

- The staff and I listened to the grandmothers' subtle indication of resistance to a "problems" focus in the assessment, and shifted to emphasizing strengths. Data collection on problems was done indirectly or in group which was more acceptable.

- We stressed validation of the grandmothers' worth as the principal goal of the assessment exercise, with data collection, analysis, and dissemination as secondary. The exercise became an empowering one for all involved.

- For the assessment, we guided the grandmothers into opportunities (consultations, meetings, lobbying) which drew out their values, opinions, experiences, and counsel on issues related to their health and well-being.

- When certain approaches met with limited success, for example, problem-posing questioning for critical analysis, we tried others to increase participant analysis such as returning individual interview data to the grandmothers in group which triggered further dialogue, and methodical individual and joint study of drafts of the report.

267

- The research was done by a team whose members developed mutual acceptance, trust, friendship, and respect. Caring relationships connected us all.

5.1.6 Indicators of Success

Our experiment with PAR demonstrated success according to a number of indicators or positive outcomes:

- Participation in the health promotion project and participatory health assessment resulted in empowering effects on the grandmothers.

- Awareness was raised in the minds of the grandmothers about issues they had not been questioning.

- Awareness was raised in the larger community about the option and value of conducting research using PAR as the methodology.

- Action was undertaken on numerous individual and social issues, making the direct link between research and community action and change, giving the grandmothers a voice and linking them with others to build alliances, and leaving behind some skills and community structure for ongoing activities, such as the Sharing Our Values workshop.

- Collective research--collecting and systematizing information-- was conducted, demystifying and reclaiming a long-time process, and shifting to a "power with" relationship between the ER and other participants.

- New knowledge was produced and disseminated using data enriched and verified by the expertise of the participants, and with results accessible to and for ownership by them.

- Through collective memory, recent history was recovered and culture and popular knowledge were given value; such affirmations of

knowledge fostered capacity-building and cohesion among the grandmothers.

5.1.7 Points of Tension

Our experiment with PAR also revealed points of tension which are viewed as dialectics and a normal part of a process to affect change.

- <u>Ownership</u> The decision to conduct research was not made by the advisory committee or grandmothers, the "problem" to be examined was not identified by them, and the control of the whole project was not theirs. Without this fundamental responsibility and commitment, the project and research were never fully owned by them.

- <u>Perception of research</u> Research carried the stigma of exploitation in the minds of the grandmothers. Our initial health assessment focus was on needs, and the grandmothers resisted being viewed as problematic. To increase acceptance of research, it was integrated with other project programming to make it resonate more with the grandmothers, but then lost some of its visibility, recognition, and replicability. Also, because of this, the full contribution of all team members is not clear, and could lead to underestimated projections for resources required for future PAR inquiries.

- <u>Use of traditions</u> Use of traditional ceremonies and practices, which could have contributed further to reclaiming history and culture, and thus to building identity, capacity, and cohesion among the grandmothers, was reduced in response to criticism by a minority voice.

- <u>Self-reliance</u> The staff and I were equivocal on the approach we took with the grandmothers--in practice catering to and doing for them, as they do with others most of the time, or keeping to principle and acting only in ways that fostered their self-reliance.

- <u>Research associates</u> The research associates added to the profile and advancement of the research, showing the feasibility and value of

269

developing specific research skills closer within the local community. Their individual problems detracted from their overall contribution, however, becoming a microcosm of the dilemma between the personal and the public.

- **Capacity** Despite the grandmothers innate and acquired strengths, their capacity to be active co-researchers was limited, and the desire of the project and the community for their involvement far surpassed their ability to respond; even gaining access to them for aspects of the research was difficult. By contrast, they enjoyed socializing, traditional events, and meeting with guests. Various grandmothers resisted commitment of a business or political nature or one that required frequent attendance. Furthermore, many were restricted because either English was not their first language or they were unaccustomed to expressing their opinions, beliefs, and feelings verbally.

- **Critical analysis** Even though problem-posing dialogue is the central strategy proposed in PAR for developing a critical understanding of people's socio-political realities, we had limited success. The grandmothers had an aversion to being questioned directly about their problems. This kind of analysis seemed like "politics" which they disliked; they had learned a "culture of silence," and our time together developing comfort and skill with this kind of dialogue was limited.

- **Conflict** When conflict occurred in the group, it was most often avoided, and not addressed or resolved. The traditional approach is to reach consensus indirectly, using the guidance of elders, but the grandmothers had varying styles, and we never established ways in which conflict would be dealt with in the project.

Our experience had many of the same challenges as St. Denis's community-based participatory research with an urban Alaska Native community. The similarity of the lessons from her work with ours is remarkable since she is an Aboriginal researcher who worked within an Aboriginal organization and with Aboriginal people. From that

270

experience, she developed guidelines to assist others in steering through these uncharted waters of participatory research with communities (see Appendix I).

5.1.8 The Role of the External Researcher

In PAR, all participants, including the ER, influence the process and outcomes, contribute skills and knowledge, experience personal growth, and participate in social change. The relationship between researcher and subjects moves from "power over" to "power with" and all participants are respected as equally knowing subjects.

My role as an ER was different with each of the groups involved:

- With the advisory committee, I facilitated the development of the research design.

- With the grandmothers, I became a part of the whole project and functioned as a nurse, educator, advocate, friend, mediator, organizer, scribe, and driver. More often than not, I set aside my specific agenda of the health assessment, and blended in with general activities. For the assessment itself, I was an advocate for research, trainer, facilitator, technician, researcher, educator, organizer, and social activist.

- With the staff, I was a colleague, planner, organizer, and educator.

- With the research associates, I was an educator and trainer, supervisor, and colleague.

- As a graduate student, I was a negotiator and mediator between the expectations of academe and the commitment to PAR.

With the central participants, the grandmothers, I was able to guide the participatory health assessment and engage them in it because we

271

developed relationships of caring and respect. These were built through regular home visits, offering respectful services, sharing common joys and pains, and seeing one another as whole persons. We developed a genuine affection for one another. I was committed to putting the grandmothers' personal and group development first, with the research proceeding only in ways supportive of that growth. The research and I served the grandmothers.

Because of the limitations imposed on the grandmothers by their own poor health, family responsibilities, and traumatic histories, my role with them demanded that I give up notions of timelines and short-term accomplishments, commit fully all the time needed to nurture development of the grandmothers and the research process, and be flexible in all things. Since this was my first experience working through PAR completely, and because my earlier attempt had been thwarted, I lived with an underlying feeling of trepidation throughout the initiative, and had to continually persuade myself to "trust the process." I did, and the process worked.

5.2 The Effects of Participation

This section summarizes the findings and discussion of the effects on the grandmothers due to their participation in the health promotion project and participatory health assessment. Again, this material has been presented previously, and is given here only to recap.

5.2.1 Findings

The findings of the primary objective regarding changes in the grandmothers from participation were portrayed in a model (see section 4.3). I organized the data into five categories of interdependent and overlapping outcomes: cleansing and healing, connecting with self, acquiring information and skills, connecting within the group, and external exposure and engagement. Furthermore, the model shows participation as the central influence on the outcomes; action as a theme

272

interwoven throughout; and opportunity, encouragement, and mediation as key characteristics of the project and health assessment environment.

The outcomes of participation were eloquently described by the grandmothers, primarily in the individual interviews conducted for this purpose. The five main categories were further composed of many subcategories.

"Cleansing and healing" included the subcategories of self-healing and self-care. This aspect of the project and research played a more prominent role than I had expected. It was more valued by the grandmothers than any other, and highlights the importance of basing consciousness-raising and socio-political change on attention to personal development. The healing circle was the central therapeutic program identified by the grandmothers, but individual counselling, traditional ceremonies, educationals, and caring relationships were also mentioned.

"Connecting with self" had subcategories of self-understanding, self-esteem, identification of strengths and needs, and cultural and spiritual identity. As women, the grandmothers had spent their lives being selfless and caring for others, and as Aboriginal people, being disparaged by the dominant society. In the project and research, opportunity and encouragement was provided to them to think about themselves, their history and traditions, their strengths and needs, their worth and wisdom, and to take time to value and enjoy themselves.

"Acquiring information and skills" included increased knowledge about health and disease, assertiveness, articulating strengths and needs, and gaining access to other resources. Through the project and research, the grandmothers engaged in activities that many of them had never been involved in before--committees, consultations, meetings, advocacy, traditional ceremonies--that expanded their knowledge, sources of support, and self-confidence.

"Connecting within the group" revealed subcategories of group identification, mutual understanding and respect, and mutual learning

273

and inspiration. Over time in the project and research, the grandmothers developed an increasing sense of group identity, cohesion, and support. Aboriginal cultures place great value on the community and, similarly, our grandmothers felt most comfortable when speaking and acting as a group. Creating community anew in the urban environment may have been the greatest contribution and outcome of the project and research.

"External exposure and engagement" included willingness to influence the system, reaching out, speaking up, and community honouring. The data showed many examples of the grandmothers' involvements beyond their immediate circles. At an individual level, all had lifelong dealings with various systems--health, education, religion, and so forth--but few had engaged externally in making change for the common good, as they did in the project and research. Conversely, few had ever been honoured by the larger community for their contribution and value, as they were here.

Data from the staff triangulated the findings from the grandmothers, verifying empowering outcomes of participation not only in the grandmothers but in themselves, and acknowledging the value of PAR. My own response, as ER, to participation was profound, restoring my joy in service, faith in the capacities of "ordinary people," strengthening my resolve to further incorporate my values and politics into academic and work life, and feeling rejuvenated as a woman.

5.2.2 Participation

Participation in many aspects, in varying degrees, is identified as the central influence of the project and research which contributed to empowering outcomes in the grandmothers. Participation led to connections with self and with others that reduced isolation, improved self worth, and formed community among the grandmothers. Also, by having the degree of control over the research that they did, research was demystified for the grandmothers and staff, and its value recognized.

5.2.3   Action

The project and research were well received by the grandmothers to a large extent because of the responsiveness to their day-to-day issues. Theoretical or objective distance was not appropriate or respectful when working within caring relationships and with people who faced many challenges.   Action is the natural partner of inquiry and reflection, and the cyclical progression of these three phases leads to personal development, group cohesion, and socio-political change.

5.2.4   Study   Environment

For the grandmothers, the project and research provided an environment of opportunity, encouragement, and mediation which fostered their empowerment.   Opportunities were created for the grandmothers to come together, heal, form community, socialize, have fun, learn, meet others, reflect on their reality, have a voice, and engage with new groups around important issues.   Encouragement was constant and caring, drawing the grandmothers together to better know themselves, gain support and strength from one another, and be part of the larger community. Mediation occurred commonly between the grandmothers and external groups, conveying the grandmothers' ideas outward and gaining access to resources to serve them.

5.2.5   The   Process

The process of the grandmothers' empowerment as an outcome of their participation in the project and research is depicted in the model of changes (see Figure 3), and was progressive but not linear, and cyclical. In some ways, Labonte's empowerment holosphere[434] describes this progression but it, too, must be viewed not as unidirectional but as cyclical, as he intended.   For example, a very shy grandmother joined the project just as we were preparing for the first Aboriginal consultations with the health district board.   She took part in the full-day workshop which closed with a ceremonial round dance, her first ever, and followed up with a subcommittee being struck to continue a focus on Aboriginal

issues, on which she has been sitting up to the time of this writing. About six months after the consultation, I conducted an individual interview with her on "problems, issues, and concerns" and she disclosed some painful past memories. A short time later, she shared this story with the rest of the grandmothers in the healing circle. Our coordinator marks the healing circle as the time that grandmother's self-confidence appeared to rise, and she became a more active participant in the project and other activities. Experience in one sphere has spin-off benefits in others.

5.2.6   Study   Strengths   and   Limitations

This case study report illuminates the phenomenon of interest--PAR in relation to health promotion. It contributes to an understanding of the process of research when conducted by ordinary people about themselves. It is one of the few studies which examines the effects of this engagement on the participants and describes these outcomes.

The description in this report is rich and complete, supplies a range of data, and is written in a narrative form to give the "flavour" of the inquiry. Trustworthiness is addressed by the detailed description of methodology, thick description provided, use of peer debriefing, and compliance with techniques to examine validity--triangulation, construct validity, face validity, and catalytic validity.[435]

The special qualities of a case study also pose restrictions in its use. Since this is a single qualitative case study, the inquiry is limited to the examination of PAR and health promotion in one case only, with one methodology, in one population, and using selected methods only. The inquiry demanded a great commitment of time in both intensity and duration. The resulting thick description may be too lengthy, too detailed, or too involved for a wide readership. The account relies heavily on my interpretation, as the primary instrument of data collection and analysis, and despite addressing techniques to enhance trustworthiness, such as peer debriefing, the representation remains mine.

276

5.3   Implications

This section reflects upon the study's significance and implications for other related work in PAR and health promotion.

Our participatory health assessment was embedded in the health promotion project and intertwined with it. This could be the reality of other related research since many people--oppressed, otherwise disadvantaged, or just leading complex, busy lives--may be unable to devote time and energy to something unless it fits in with other demands, activities, or supports in their lives. Thus, rather than be a separate initiative, it may be advisable for PAR to be associated with other programming to build in service and support to participants as they research and respond to challenges in their lives.

At a grassroots level, our work demonstrated that power relations can be altered and people's knowledge valued. The conventional power differential between researcher and subjects was reduced, and all participants worked as peers and colleagues with responsibilities and contributions shared. The report of the health assessment was largely the words of the grandmothers, and the analysis and presentation was reviewed and revised by them repeatedly. Yet researchers who intellectually accept power-sharing may find it threatening in practice and actually undermine it. Furthermore, even ideological proponents of community control and capacity may find themselves questioning the value and validity of ordinary people's knowledge when it is produced outside a dominant research paradigm.[436] Sharing power and crediting people's knowledge may be harder to practise than profess.

Research is a process which was natural to all societies for their survival but has become the purview of academics. Through this participatory health assessment, research began to be demystified for participants who had the experience of working in a team to conduct their own research. When provided with the opportunity, tools, and support, ordinary people can indeed conduct research that is meaningful to them and contributes to personal and social change. Nonetheless, to transform the negative

277

impression of research held by marginalized people will be needed further similar experiences with respectful, participatory, and responsive research. Moreover, for the research process and findings to be empowering and health promoting, participation and power-sharing must be increasingly emphasized in more research.

This study supports other literature[437] which shows the relationship between empowerment and health, and highlights particular aspects. The process of personal empowerment--of increasing awareness, confidence, and voice--is as important as other political successes of a more tangible nature. Given other opportunities for organizing in the future, the grandmothers may be able to build on the personal and group progress made so far. Considering their age and the pace of change, any socio-political effects from their activity would likely benefit the grandmothers less than it would the upcoming generations. Socio-political activity may be important for the grandmothers if it allows them to transcend their immediate personal situations even episodically. However, as mentioned earlier, in Chapter 2 as a challenge in PAR, raising the political consciousness of the grandmothers carries risks since the socio-political climate may prevent change for which they are striving and lead to greater discouragement than what they experienced before.

When working with people like the grandmothers who have been oppressed and silenced, an aspect of PAR that needs attention is what is not said. Other opportunities need to be created which will further give voice to that which is not readily expressed. Furthermore, bringing people together who have been isolated and providing them with a chance, fostered by safety and compassion, to share their experiences, recognize their resiliency, and heal themselves is empowering, and may be one of the greatest contributions of PAR.

For PAR to achieve greater acceptance and legitimacy, more of it must be done, with many different communities, in different fields, and around a variety of issues. Because each case will be unique and not generalizable, many studies of a particular phenomenon need to be done so that each

may form a chain leading to cumulative grounded theory. These studies need to be better communicated to both researchers and community groups who would then have the experience of others to expose them to this paradigm, and to inform them about the methodology. Furthermore, there needs to be an incisive and fair critique of conventional research and an equally clear and astute description of alternatives, all in a form and language accessible to both researchers and communities.[438]

The project and our health assessment, in keeping with the true meaning and essence of health promotion, created opportunities and nurtured skills so that the grandmothers healed themselves, supported each other, and experienced success in advocating for improvement in their personal and collective lives. As Green[439] described, the interaction between perceived and actual control is an upward spiral in empowerment where there are opportunities for people to succeed, small successes are achieved, and capabilities are recognized. This approach is the intended socio-ecological focus of health promotion. When this focus is changed, however, to selective life style change campaigns, it no longer respects or serves people's holism. Despite all the theoretical frameworks and rhetoric of health promotion, policy-makers and funders continue to support narrow, behaviour-change, short-term initiatives. Our work demonstrates the value and success of holistic participatory research and programming, and the potential for more health enhancing results with sustained support.

The most effective PAR outcomes are seen in established groups; therefore, where they do not exist, support for the creation of such community organizations is necessary.[440] In the PAR model, group identity, structure, and function are prerequisites, a result of the process, and the vehicle to sustain the outcomes. If a group is not yet in place, the time committed to the initiative must include enough start-up time to form and build a group with caring and trusting relationships on which to base research.

To embark on PAR for graduate studies is a risk. The academic institution may have difficulty giving legitimacy to research controlled by ordinary

people producing their own science and knowledge. The time needed may not be manageable for all students and programs. Funding sources of student fellowship may not yet be persuaded of the value of PAR or not accept an open-ended proposal. The unpredictable process and results give a constant element of uncertainty to the whole experience which may be unnerving for the student and supervising committee, and produce outcomes at variance with the proposed questions. Yet, experiences like mine may assuage these concerns and reassure the interested and committed that PAR is doable.

An ER in PAR cannot be a detached scientist with a well-defined agenda and timetable but must be willing, indeed enjoy immersing her/himself in the lives of the participants. It helps to have a philosophical commitment to the people and their issues. For me, because of my own children, my work in developing countries and with Aboriginal people, my belief in social justice, and my interest in women's oppression, working with the grandmothers was a natural and satisfying fit which sustained my interest and involvement for the long-term. Furthermore, researchers and practitioners need to recognize political activity as part of our professional mandate, bringing our personal belief system closer in line with our work life. If we believe in social justice and people-centred development, our research and practice should reflect those values.

When working cross-culturally and representing the oppressors of a colonized society, an ER faces a delicate balance--how to appropriately guide, provoke, and use skills without dominating, distorting, or controlling. I found myself in an ongoing state of self-censorship, scrutinizing the words I used, the roles I played, and the direction and pace I was steering. Representing the stereotypical "Whites" was a burden which was relieved over time as the grandmothers, staff, and I became individuals, peers, and friends to one another, but the image would reappear from time to time and remind me of who I was and the differences our histories brought to the picture. Increasing trust did dispel the barrier most of the time, and we became personal and professional colleagues. Additionally, the benefits are enormous,

280

producing rich portrayals of real life phenomena, an experience that is enjoyable and rewarding, and the satisfaction of knowing that one's pursuits empowered rather than exploited others.

Despite the accomplishments of this project and research, the effects only extended to knowledge and skills development in some areas and are likely temporary without sustained opportunities for continued personal growth, mutual support, inquiry, reflection, and action. Translating processes and outcomes from one PAR initiative to have a broader impact in the lives of oppressed Aboriginal people is unlikely, at least in the short term.[441] Ongoing resources are needed to keep building and strengthening a community whose members, like the grandmothers, are debilitated by poor health and who continue to suffer from societal barriers due to their race, culture, age, sex, and economic status. With such resources, the sustained outcomes would be well worth the investment for society at large. If this grandmothers' project were to be continued, there would be benefits for both our city at large and the Aboriginal people within it: enhanced cultural identify, reinstatement of a respected place for the elderly, a functioning role of the grandmothers in guidance and support of the young,* elevated status and honoured voice of this group, and a healthier subpopulation contributing to a more prosperous life over all.

Faith in the long-term process is essential for all participants because social and political change does not occur readily. Each PAR initiative needs to be viewed not in terms of whether it creates "the revolution," which is unlikely and may be discouraging, but whether it contributes to individuals' well-being and thus to a better society. Change is a process not an event[442] and many small successes contribute to transformation. As Margaret Mead is popularly credited with saying: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."

5.4 Further Research Questions

This last section poses questions remaining for future research which arise from this work.

How would PAR for health promotion be experienced and what would be its outcomes when used in a different population group, in a different setting, or to address a different question?

How else can PAR contribute to health promotion, for example, with health district management and staff as participants challenged to ameliorate job stress in their work environment for the improved health of all?

How can an ER influence a community development process so that PAR emerges as a natural initiative rather than being a preset, imposed objective? How would a PAR initiative be different if it did arise this way? How can an ER function so as to be "on tap" rather than "on top"?

How can PAR develop as a purely internal activity with all researchers coming from the participant group? How can local leadership be fostered to this end?

What techniques are effective for attracting grassroots participants into PAR and deepening a critical analysis of their social reality? How can techniques be identified and used that are more traditional and vernacular ways of interaction and leadership?

What would other related case studies contribute to the understanding of PAR as an approach to research and intervention for health promotion, and would this lead to cumulative grounded theories?

This concludes my thesis of this case study, with the invitation to others to follow this interesting path and rewarding journey of working with people to better know and improve our realities.

<u>Endnotes</u>:

*   A study conducted by 13 Aboriginal youths and five adults of the Nishnawbe-Aski Nation, which represents 49 communities across northern Ontario, concluded that Aboriginal youth want their parents and elders to be supportive of them to help control high levels of youth suicide. "Youth need to know that they belong and are cared for. . . . Giving this message to the youth, clearly and consistently must be priority" (local newspaper, July 24, 1996).

References

1   Hancock T, Draper R (1989).   Participatory research: a key strategy for health promotion. Unpublished paper. 1989. Request from Hancock, Box 428, Kleinburg, Ontario L0J 1C0.

2   Fals-Borda O, Kemmis S.   Investigating reality in order to transform it: a conversation with Orlando Fals-Borda and Stephen Kemmis [videorecording].   Calgary (AB): University of Calgary, Communications Division, 1990.

3   Lather P.   Issues of validity in openly ideological research: between a rock and a soft place.   Interchange 1986b; 17(4):63-84; p. 63.

4   Cancian F, Armstead C. Participatory research: an introduction. Unpublished paper 1990.   Request from authors at the Department of Sociology, University of California, Irvine, CA, 92717, USA.

5   Pyrch T.   Participatory action research (PAR): a perspective. Workshop handout presented at the International Community Development Conference; 1991 July; Saskatoon (SK). Request from author at Continuing Education, University of Calgary, Calgary Alberta, T2N 1N4, Canada.

6   Colorado P.   Bridging Native and Western science.   Convergence 1988; 21(2/3):49-68.

7   Fals-Borda O, Rahman M A, editors.   Action and knowledge: breaking the monopoly with participatory action-research.   New York: The Apex Press, 1991.

8   Health promotion in action [editorial].   Health Promotion, 1986; 1(2):187-190; p. 187.

9   Hancock.   Participatory research.

10   Kirby S, McKenna K. Experience, research, social change: research from the margins.   Toronto: Garamond Press, 1989.

11   Janesick V J.   The dance of qualitative research design: metaphor, methodology, and meaning.   In: Denzin NK, Lincoln YS, editors. Handbook of qualitative research.   Thousand Oaks: Sage, 1994:209-219.

12   Huberman AM, Miles MB.   Data management and analysis methods. In: Denzin NK, Lincoln YS, editors. Handbook of qualitative research.   Thousand Oaks: Sage, 1994; p. 438.

13   Gerrard N.   Some painful experiences of a White feminist therapist doing research with women of colour.   In Adelman J,

Enguidanos G, editors. Racism in the lives of women: testimony, theory, and guides to anti-racist practice. New York: The Haworth Press, 1995.

14   Haig-Brown C. Choosing border work. Canadian Journal of Native Education 1992; 19(1):9-16.

15   Haig-Brown C. Border work. In: New WH, editor. Canadian literature: special issue. Native writers and Canadian writing. Vancouver: UBC Press, 1990

16   Gerrard N. Racisim and sexism, together, in mental health systems: the voices of women of colour [doctoral thesis]. Toronto: University of Toronto, 1990.

17   Katz, R. Hearing healers: the contribution of vulnerability to field research. In Katz R, Gonzalez CA, Murphy-Shigamatsu S, Naquin V, Nunez-Molina M, Seth N, editors. Synergy and healing: perspectives on transformation and social change. Saskatoon (SK): Saskatchewan Indian Federated College. Unpublished. Request from author, c/o SIFC, 710 Duke Street, Saskatoon, SK, S7K 0P8.

18   ibid, p. 68

19   ibid, p. 68

20   Smith S E. Dancing with conflict: public health nurses in particatory action-research [doctoral thesis]. Calgary (AB): University of Calgary, 1995.

21   Maguire P. Doing participatory research: a feminist approach. Amherst (MA): Center for International Education, 1987.

22   Freire P. Pedagogy of the oppressed. New York: Continuum, 1970.

23   Smith. Dancing with conflict.

24   Bellah R, Madsen R, SullivanW, Swidler A, Tipton S. Habits of the heart. Los Angeles: University of California Press, 1985; p. 333.

25   Bailey K D. Methods of social research. 3rd ed. New York: The Free Press, 1987.

26   Labonte R, Robertson A. Delivering the goods, showing our stuff: the case for a constructivist paradigm for health promotion research and practice. Health Education Quarterly 1996; 23(4):431-447.

27   Reason P, Rowan J, editors. Human inquiry: a sourcebook of new paradigm research. New York: John Wiley, 1981.

28   Lather P. Research as praxis. Harvard Educational Review 1986a; 56(3): 257-277.

29   Buchanan D. An uneasy alliance: combining qualitative and quantitative research methods. Health Education Quarterly 1992; 19(1): 117-135.

30   Hall, B. Participatory research, popular knowledge and power: a personal reflection. Convergence 1981: 14(3):6-17.

31   Smith, JK. Quantitative versus qualitative research: an attempt to clarify the issue. Educational Researcher 1983; March:6-13.

32   Guba E G, Lincoln Y S. Fourth generation evaluation. Newbury Park: Sage, 1989.

33   Buchanan. An uneasy alliance.

34   Buchanan D. Reflections on the relationship between theory and practice. Health Education Research: Theory and Practice 1994; 9(3):273-283.

35   Guba. Fourth generation evaluation.

36   Hall B. Participatory research, popular knowledge and power: a personal reflection. Convergence 1981; 14(3):6-17.

37   Harman WW. The transpersonal challenge to the scientific paradigm: the need for a restructuring of science. ReVision 1988; 11(2):13-21.

38   Labonte. Delivering the goods.

39   Lather. Research as praxis.

40   Lewis F. Whom and from what paradigm should health promotion serve? Health Education Quarterly 1996; 23(4):448-452.

41   Reason. Human inquiry.

42   Smith. Quantitative versus qualitative.

43   Smith. Dancing with conflict.

44   ibid

45   Guba EG.   The paradigm dialog.   Newbury Park: Sage, 1990.

46   Labonte. Delivering the goods.

47   Smith. Dancing with conflict.

48   Harman. The transpersonal challenge.

49   Hall. Participatory research; p.8

50   Smith. Quantitative versus qualitative.

51   Buchanan. An uneasy alliance.

52   Gerrard. Some painful experiences.

53   Reinharz S. On becoming a social scientist.   San Francisco: Jossey-Bass, 1979.   Cited in Lather. Research as praxis.

54   Lather. Issues of validity.

55   Hall.   Participatory research.

56   Hall.   Participatory research.

57   Lather. Research as praxis.

58   Buchanan.   Reflections.

59   Harman.   The transpersonal challenge.

60   Lindblom C. Inquiry and change: the troubled attempt to understand and shape society.   New Haven: Yale University Press, 1990.

61   Buchanan.   Reflections.

62   Harman. The transpersonal challenge.

63   Labonte. Delivering the goods.

64   Lewis. Whom and from what.

65   Cancian. Participatory research.

66   Maguire. Doing participatory research.

67   Tandon R. Participatory research in the empowerment of people. Convergence 1981; 14(3):20-27.

68   Mies M. Towards a methodology for feminist research. In: Bowles G, Duelli-Klein R, editors. Theories of Women's Studies. Boston: Routledge and Kegan Paul, 1983:357-366.

69   Fals-Borda. Action and knowledge.

70   Tandon. Participatory research.

71   Hall. Participatory research.

72   Cancian. Participatory research.

73   Mies. Towards a methodology.

74   Cancian. Participatory research.

75   Hall. Participatory research.

76   Freire. Pedagogy.

77   Lather. Issues of validity; p.73

78   Lather. Research as praxis.

79   Hall. Participatory research.

80   Brown D, Tandon R. Interviews as catalysts. Journal of Applied Psychology 1978; 63(2):197-205. Cited in Lather. Issues of validity; p. 73

81   Fals-Borda. Action and knowledge.

82   ibid; p. 152.

83   ibid; p. 153.

84   Cancian. Participatory research.

85   ibid.

86   Lather. Research as praxis.

87   Park P, Brydon-Miller M, Hall B, Jackson T, editors. Voices of change: participatory research in Canada. Toronto: Ontario Institute for Studies in Education, 1993.

88   Cancian.   Participatory   research.

89   Merrifield J. Putting scientists in their place: participatory research in environmental and occupational health.   In: Park P, Brydon-Miller M, Hall B, Jackson T, editors.   Voices of change: participatory research in Canada. Toronto: Ontario Institute for Studies in Education, 1993: 65-84;   p. 67.

90   Cancian.   Participatory   research.

91   Kent G. Nutrition education as an instrument of empowerment. Journal of Nutrition Education 1988; 20(4):193-195.

92   Rappaport J. Terms of empowerment/exemplars of prevention: toward a theory for community psychology.   American Journal of Community Psychology 1987;15:2.

93   Tandon R. Social transformation and participatory research. Convergence 1988; 21(2/3):5-15.

94   Gaventa J. Participatory research in North America. Convergence 1988; 21(2/3):19-27.

95   Cancian.   Participatory   research.

96   Kieffer CH. Citizen empowerment: a developmental perspective. Prevention in Human Services 1984; 3(2/3):9-36.

97   Lord J, McKillop Farlow D. A study of personal empowerment. Health Promotion 1990; Fall:2-8.

98   Tandon.   Social   transformation.

99   Cancian.   Participatory   research.

100   ibid

101   Maguire.   Doing   participatory   research.

102   Cancian. Participatory research; p. 21.

103   ibid

104   Tilakaratna S. Stimulation of self-reliant initiatives by sensitized agents: some lessons from practice.   In: Fals-Borda O, Rahman MA, editors. Action and knowledge: breaking the monopoly with participatory action-research.   New York: The Apex Press, 1991:135-145.

105   Smith. Dancing with conflict.

106   Green LW, George MA, Daniel M, Frankish CJ, Herbert CJ, Bowie
       WR, O'Neill M. Study of participatory research in health
       promotion: review and recommendations for the development of
       participatory research in health promotion in Canada.
       Vancouver: Institute of Health Promotion Research, University of
       British Columbia and the B. C. Consortium for Health Promotion
       Research, 1994:1.

107   Maguire. Doing participatory research.

108   Kinsey D. Dialogue is not a chaste event: comments by Paulo
       Freire on issues in participatory research.   Amherst (MA): The
       Center for International Education, 1985.

109   Park, P. What is participatory research? A theoretical and
       methodological perspective.   In Park.   Voices of change:1-20.

110   Freire. Pedagogy.

111   Comstock DE Fox R.   Participatory research as critical theory: the
       North Bonneville, USA, experience.   In Park.   Voices of
       change:103-124.

112   Little D.   Taking a critical stance toward the development of a
       nursing curriculum.   Unpublished presentation   to Saskatchewan
       Registered Nurses Association; Regina(SK); 1994 May 9.   Request
       from author at University of Regina, Regina, SK, Canada.

113   Smith. Dancing with conflict.

114   Fals-Borda. Action and knowledge; p. 4.

115   Starhawk.   Truth or dare: encounters with power, authority, and
       mystery.   New York: Harper Collins, 1987

116   Smith. Dancing with conflict; p. 14.

117   Antovosky A. Health, stress, and coping.   San Francisco: Jossey-
       Bass Publishers, 1979; p. 187.

118   Lame Deer J, Erdoes R.   Lame Deer: seeker of visions.   New York:
       Washington Square Press, 1972.

119   Srinivasan L.   Options for educators: a monograph for decision-
       makers on alternative participatory strategies.   New York:
       PACT/CDS, Inc., 1992.

120   Smith. Dancing with conflict; p. 9.

121   ibid; p. 10

122   Freire. Pedagogy.

123   Smith. Dancing with conflict; p. 11.

124   Mies. Towards a methodology; p. 124.

125   Kirby and McKenna. Experience; p. 25.

126   Freire. Pedagogy; p. 106.

127   ibid; p.17.

128   Freire P.   The politics of education.   South Hadley (MA): Bergin
      and Garvey Publishers, 1985; p. 93.

129   Freire. Pedagogy; p. 18.

130   Fals-Borda. Action and knowledge; p. 4.

131   ibid; p. 11.

132   Comstock. Participatory research.

133   ibid; p. 112.

134   Maguire. Doing participatory research.

135   Hall B.   Introduction.   In: Park. Voices of change:xiii-xxii; p. xvi.

136   Maguire P. Challenges, contradictions, and celebrations:
      Attempting participatory research as a doctoral student.   In: Park.
      Voices of change:157-176; p. 163

137   Maguire. Doing participatory research.

138   Maguire. Challenges.

139   Marshall J P. Participatory research: a model for initiating
      problem-solving education in the community.   Unpublished
      paper, 1981.   Cited in: Maguire. Doing participatory research.

140   Horton B.   On the potential of participatory research: an
      evaluation of a regional experiment.   Unpublished paper, 1981.
      Cited in: Maguire. Doing participatory research.

141   Tandon. Participatory research.

142   Barndt D. Connecting immigrant workers: community self-portraits. Presented at the International Forum on Participatory Research, Ljubljana, Yugoslavia, 1980. Cited in: Park. Voices of change.

143   Conchelos G, Kassam Y. A brief review of critical opinions and responses on issues facing participatory researchers. Convergence 1981; XIV (3): 52-63.

144   Minkler M. Ethical issues on community organization. Health Education Monograph 1987; 6(2):198-210.

145   Jackson. A way of working.

146   Heaney T. If you can't beat 'em, join 'em: the professionalization of participatory research. In: Park. Voices of change:41-46.

147   Fals-Borda O. Science and the common people. Presented at the International Forum on Participatory Research, Ljubljana, Yugoslavia, 1980. Cited in Comstock. Participatory research.

148   Moser H. Action research: Experiences from a Swiss project. Presented at the International Forum on Participatory Research, Ljubljana, Yugoslavia, 1980. Cited in: Comstock.

149   Barndt. Connecting immigrant workers.

150   Mduma . Appropriate technology; p. 109.

151   Mbilinyi. My experience as woman; p. 109.

152   Cain BJ. Participatory research: research with historical consciousness. Toronto: Participatory Research Project of the International Council for Adult Education, 1977. Cited in Comstock; p. 109.

153   Hancock & Draper. Participatory research.

154   ibid

155   Jackson. A way of working; p. 63.

156   Miller JR. Skyscrapers hide the heavens: a history of Indian-White relations in Canada. Toronto: University of Toronto Press, 1989: jacketcover.

157   Jackson. A way of working; p. 53.

158   ibid; p. 63.

159   ibid; p. 61.

160   Lewis F. The concept of control: a typology and health related variables (personal communication), 1986.   Cited in Tones K. Health promotion, empowerment and the psychology of control. Journal of International Health Education 1991; 29(1):17-26.

161   Rodin J.. Aging and health: effects of the sense of control. Science 1986; 233: 1271-1276.

162   Schultz R. Aging and control. In: Garber J, Seligman M. Human helplessness: theory and applications.   New York: Academic Press, 1980.

163   Tones K. Health promotion, empowerment and the psychology of control.   Journal of International Health Education 1991; 29(1):17-26.

164   Wallerstein N.   Powerlessness, empowerment, and health: implications for health promotion programs.   American Journal of Health Promotion 1992; 6(3):197-205.

165   Langer E J.   The psychology of control.   Beverley Hills: Sage Publications, 1983.

166   Gaventa J. Power and powerlessness: quiescence and rebellion in an Appalachian valley.   Chicago: University of Illinois Press, 1980.

167   Rotter JB. Some problems and misconceptions related to the construct of internal versus external control of reinforcement. Journal of Consulting and Clinical Psychology 1975; 43(1):56-67.

168   Bandura A. Self-efficacy: towards a unifying theory of behavioral change.   Psychological Review 1977; 84:191-215.

169   Bandura A.   Social foundations of thought and action: a social cognitive theory.   Englewood Cliffs, NJ: Prentice-Hall, 1986.

170   Seligman MEP.   Helplessness: on depression, development and death.   San Francisco: W.H. Freeman, 1975.

171   Tones. Health promotion.

172   Strecher VJ, De Vellis BMcE, Becker M.H, Rosenstock IM. The role of self-efficacy in achieving health behavior change.   Health Education Quarterly 1986; 13:73-91.

173   Lalonde, M. A new perspective on the health of Canadians. Health and Welfare Canada, 1974.

174   Ottawa charter for health promotion. World Health Organization, Health and Welfare Canada, Canadian Public Health Association, 1986.

175   Green K. Control, empowerment, and health promotion. Paper presented at the 82nd Annual Conference of CPHA, 1991, June; Regina, (SK). p. 1. Request from author at Dept. of Community Health and Epidemiology, College of Medicine, University of Saskatchewan, Saskatoon, SK, Canada.

176   ibid

177   ibid

178   Tones. Health promotion.

179   Wallerstein. Powerlessness; p. 197.

180   ibid; p. 197.

181   Seeman M. On the meaning of alienation. American Sociological Review 1959; 24:783-791.

182   Wallerstein. Powerlessness; p. 199.

183   Kieffer. Citizen empowerment; p. 16.

184   Lord. A study of personal emowerment.

185   Freire. Pedagogy.

186   Wallerstein. Powerlessness; p. 202.

187   Kent. Nutrition education.

188   Kieffer. Citizen empowerment; p. 18.

189   Lord. A study of personal empowerment.

190   Kieffer. Citizen empowerment.

191   Wallerstein. Powerlessness; p. 202.

192   Kieffer. Citizen empowerment.

193   Lord. A study of personal empowerment.

194   Hudson G. Women's participatory research in the Kayahna area. Unpublished presentation at the International Forum on Participatory Research, Ljubljana, Yugoslavia, 1980. Cited in: Comstock.   Participatory research; p. 109.

195   Conchelos G, Jackson T. Participatory research for community education: comparing urban and rural experiences. Unpublished presentation to the Canadian Community Education Conference, Brandon, Manitoba, 1980. Cited in: Comstock.   Participatory research;
       p. 109.

196   Joe R. Poems of Rita Joe. Halifax: Abanaki Press, 1978. Cited in Miller. Skyscrapers. Jacketcover.

197   Miller. Skyscrapers. p. x.

198   ibid.; p. ix.

199   Freire. Pedagog; p. 133.

200   ibid; p. 107.

201   ibid; p. 133.

202   ibid; p. 134.

203   Jackson. A way of working; p. 49.

204   Freire. Pedagogy; p. 163.

205   ibid; p. 161.

206   ibid; p. 160.

207   Jackson. A way of working; p. 61.

208   ibid; p. 61.

209   Insight Canada (pollsters), 1996.

210   Kirby. Experience; p. 7.

211   ibid

212   Maguire. Doing participatory research; p. 142.

213   Brant Castellano, MB (1993). Aboriginal organizations in Canada: integrating participatory research. In: Park. Voices of change:145-156; p. 145.

214   ibid; p. 145.

215   Fals-Borda. Action and knowledge; p. 149.

216   Kirby. Experience; p. 27.

217   Barnsley J, Ellis D. Research for change: participatory action research for community groups. Vancouver: The Women's Research Centre, 1992.

218   Cancian. Participatory research.

219   Fernandes W, Tandon R, editors. Participatory research and evaluation: experiments in research as a process of liberation. New Delhi: Indian Social Institute, 1981. Cited in Maguire. Doing participatory research.

220   Vio Grossi F, Martinic S, Tapia G, Pascal I. Participatory research: theoretical frameworks, methods, and techniques. International Council for Adult Education, 1983. Cited in Maguire. Doing participatory research.

221   Maguire. Doing participatory research.

222   Smith. Dancing with conflict.

223   Cancian. Participatory research.

224   Brydon-Miller. Breaking down barriers; p. 128.

225   Maguire. Challenges; p. 175.

226   Fals-Borda. Action and knowledge; p. 4.

227   Mduma in Park. Voices of change; p. 109.

228   Mbiliny in Park. Voices of change; p. 109.

229   Cain in Park. Voices of change; p. 109.

230   Senior Citizens' Provincial Council. A study of the unmet needs of off-reserve Indian and Metis elderly in Saskatchewan, 1988.

231   Park. What is participatory research? p. 19.

232   Denzin NK. The art and politics of interpretation. In: Denzin. Handbook of qualitative research:500-515; p. 513.

233   Gaventa J. The powerful, the powerless, and the experts: Knowledge struggles in the information age. In Park. Voices of change:21-40.

234   Pascal. Thoughts. Cited in Fals-Borda. Action and knowledge; p. 150.

235   Kirby. Experience.

236   Denzin NK. The research act: a theoretical introduction to sociological methods. Chicago: Aldine, 1970.

237   Kirby. Experience; p. 66.

238   ibid; p. 68.

239   Oakley A. Interviewing women: a contradiction in terms. In: Roberts H, editor. Doing feminist research. Boston: Routledge and Kegan Paul, 1981:30-61; p. 48.

240   Freire. Pedagogy.

241   Janesick VJ. The dance of qualitative research design: metaphor, methodolatry, and meaning. In: Denzin. Handbook of qualitative research:209-219.

242   Sapp A. A Cree life: the art of Allen Sapp. Vancouver: J. J. Douglas Ltd, 1977.

243   Fals-Borda. Action and knowledge; p. 150.

244   Mies. Towards a methodology; p. 128.

245   Kirby. Experience; p. 80.

246   Merriam SB. Case study research in education: a qualitative approach. San Francisco: Jossey-Bass Publishers, 1988.

247   Kirby. Experience.

248   Carney TF. Qualitative methods in communication studies: a new paradigm research manual. Windsor: Department of Communication Studies, University of Windsor, 1983. Cited in: Kirby. Experience; p. 58.

249   Finson SD.   On the other side of silence: patriarchy, consciousness
       and silence: some women's experience of theological education
       [thesis]. Boston: Boston University, 1985.   Cited in: Kirby.
       Experience; p. 117.

250   Freire. The politics of education; p. 51.

251   Huberman. Data management.

252   Kirby. Experience; p. 139.

253   Morse J. Analyzing unstructured interactive interviews using the
       Macintosh Computer.   Qualitative Health Research 1991; 1(1):117-
       122.

254   Park. What is participatory research? p. 14.

255   Kirby. Experience; p. 155.

256   Park. What is participatory research? p. 15.

257   Kirby. Experience;   p. 71.

258   Maguire. Challenges; p. 161.

259   Merriam. Case study research; p. 7.

260   Yin RK.   Case study research: design and methods.   Newbury Park
       (CA): Sage, 1984.

261   Stake RE.   Case studies. In: Denzin. Handbook of qualitative
       research: 236-247; p. 236.

262   Stebbins R. Concatenated explorations: notes on a neglected type
       of longitudinal research.   Quality and Quantity 1992; 26:435-442; p.
       439.

263   Stake. Case studies; p. 238.

264   ibid; p. 237.

265   Kemmis S. The imagination of the case and the invention of the
       study. In: Case study: an overview. Case study methods 1 (Series).
       Victoria, Australia: Deakin University Press; 1983:108-109.

266   Lincoln YS, Guba EG.   Naturalistic inquiry.   Newbury Park (CA):
       Sage, 1985.

267   Yin. Case study design.

268   Merriam. Case study research.

269   Huberman. Data management.

270   Morse. Analyzing unstructured.

271   Merriam. Case study research; p. 133.

272   Huberman. Data management.

273   Guba EG, Lincoln YS. Epistemological and methodological bases of naturalistic inquiry. ECTJ 1982; 30(4):233-252.

274   Lather. Research as praxis; p. 270.

275   Merriam. Case study research.

276   Guba EG, Lincoln YS. Effective evaluation. San Francisco: Jossey Bass, 1981.

277   Stebbins. Concatenated research.

278   Stake. Case studies.

279   Cancian. Participatory research.

280   Freire P. Foreward. In: Park. Voices of change; p. x.

281   Comstock. Participatory research; p. 109.

282   Cancian. Participatory research.

283   Ornelas A, in personal communication, 1994, with Smith. Dancing with conflict.

284   Jackson. A way of working; p. 63.

285   Allen PG. Angry women are building: issues and struggles facing Native American women. In: Cole J, editor. All American Women. Free Press, 1986:407-409.

286   Green R. Native American women: a contextual bibliography. Bloomington: Indiana University Press, 1983:14.

287   Barndt. Connecting immigrant workers; p. 109.

288   Jackson. A way of working.

289   Hancock. Participatory research.

290   Smith. Dancing with conflict; p. 9.

291   ibid

292   Gianotten V, de Wit T. Organizacion campesina: el objeto politico de la educacion popular y la investigacion participativa. Amsterdan: DECLA, Latin American Studies 30, 1985. Cited in: Fals-Borda. Action and knowledge; p. 69.

293   Nahanni P. The mapping project. In: Watkins M, editor. Dene nation: the colony within. Toronto: University of Toronto Press, 1977:21-27; p. 23. Cited in: Park. Voices of change; p. 51.

294   Herbert CP. Community-based research as a tool for empowerment: the Haida Gwaii diabetes project example. Canadian Journal of Public Health 1996; 87(2):109-112.

295   St. Denis V. A process of community-based participatory research: a case study [master's thesis]. Fairbanks: University of Alaska, 1989.

296   St. Denis V. Personal communication, 1996.

297   Maguire. Doing participatory research; p. 166.

298   Park. What is participatory research? p. 11.

299   Freire. Pedagogy; p. 149.

300   ibid; p. 89.

301   ibid; p. 145.

302   Maguire. Doing participatory research; p. 56.

303   Jackson. A way of working.

304   Kirby. Experience; P. 64.

305   Lorde A. Sister outsider. New York: Crossing Press, 1984, p. 114.

306   Maguire. Doing participatory research; p. 171.

307   ibid; p. 56.

308   de Roux GI. Together against the computer: PAR and the struggle of Afro-Colombians for public service. In: Fals-Borda. Action and knowledge:37-53; pg. 38

309   Fals-Borda. Action and knowledge; p. 149.

310   Kirby. Experience; p. 28.

311   Park. What is participatory research? p. 13.

312   Freire P. Cited in: Kinsey. Dialogue is not a chaste event; p. 12.

313   ibid.

314   Maguire. Doing participatory research; p. 174.

315   Fals-Borda O. Science and the common people. Presented at the International Forum on Participatory Reseaearch, Ljubljana, Yugoslavia, 1980. Cited in: Park. Voices of change; p. 107.

316   Freire. Pedagogy; p. 122.

317   Fals-Borda. Action and knowledge; p. 149.

318   Maguire. Doing participatory research; p. 244.

319   Brant Castellano. Aboriginal organizations; p. 153.

320   Fals-Borda. Action and knowledge.

321   ibid.

322   Heaney. If you can't beat 'em; p. 41.

323   ibid; p. 41.

324   Fals-Borda O. Cited in: Park. Voices of change; p. x.

325   Fals-Borda. Action and knowledge.

326   Galeano E. Las venas abiertas de America Latina. Mexico: Siglo XXI, 1978. Cited in: Fals-Borda. Action and knowledge; pg. 57.

327   Park. What is participatory research? p. 17.

328   Gaventa. The powerful, the powerless, and the experts; p. 127.

329   Kirby. Experience; p. 97.

330   Heaney. If you can't beat 'em; p. 41.

331   Kirby. Experience; 1989.

332   Tandon R. Cited in: Maguire. Doing participatory research; p. 157.

333   Ornelas A, 1994. Cited in: Smith. Dancing with conflict.

334   Jackson T, McCaskill D, Hall B. Introduction. Canadian Journal of Native Studies 1982; 2(1):1-9; p. 5.

335   Brant Castellano. Aboriginal organizations; p. 153.

336   Park. What is participatory research? p. 9.

337   Jackson. A way of working.

338   Kirby. Experience.

339   Griffin S. The way of all ideology. Signs: Journal of Women in Culture and Society 1982; 7(3):641-60.

340   Maguire. Doing participatory research.

341   Labonte R. #3 Health promotion and empowerment: Practice frameworks. Toronto: Centre for Health Promotion, University of Toronto, 1993.

342   Maguire. Challenges; p. 175.

343   Shah C, Farkas C. The health of Indians in Canadian cities: a challenge to the health care system. Canadian Medical Association Journal 1985; 133:859-863.

344   St. Denis. A process of CBPR.

345   Gerrard. Racism and sexism.

346   Gerrard N. To survive is to resist: resistance as achievement for women of colour clients in mental health systems. In: Gallivan J, Crozier S, Lalande V, editors. Women, girls, and achievement. North York: Captus University Publishing, 1994:50-55.

347   Maslow A. Toward a psychology of being. 2nd ed. New York: D. Van Nostrand Company, 1968.

348   Srinivasan L. Options for educators: a monograph for decision-makers on alternative participatory strategies. New York: PACT/CDS, Inc., 1992; p. 6.

349   Henderson DL. Consciousness raising in participatory research: method and methodology for emancipatory nursing inquiry. Advances in Nursing Science 1995; 17(3):58-69; p. 62.

350   Lindsey E, McGuinness L. Significant elements of community involvement in participatory action research: evidence from a community project. University of Victoria School of Nursing, 1996.

351   Dewey J. Experience and education. New York: Collier Books, 1977. Cited in: Srinivasan. Options for educators; p. 70.

352   Maslow, Toward a psychology of being. Cited in: Srinivasan. Options for educators; p. 41.

353   Romeder JM. The self-help way: mutual aid and health. Ottawa: Canadian Council on Social Development, 1990; p. 82.

354   Labonte R, Feather J. Handbook on using stories in health promotion practice. Ottawa: Health Canada, 1996; p. 5.

355   Sheilds L. Women's experiences of the meaning of empowerment. Qualitative Health Research 1995; 5(1):15-35.

356   Srinivasan. Options for educators; p. 60.

357   Romeder. The self-help way; p. 58.

358   ibid; p. 58.

359   Lord. A study of personal empowerment.

360   Berger G. The Cognito in Husserl's philosophy. Evanston: Northwestern University Press, 1972. Cited in: Srinivasan. Options for educators; p 70.

361   Romeder. The self-help way.

362   ibid; p. xi.

363   ibid; p.1.

364   ibid; p. xv.

365   ibid; p. 38.

366   ibid; epilogue.

367   ibid; p. 85.

368   ibid.

369   Hanson LM.   Participation for transformation: experiences and effects of participation in a work-study program for community development and participatory action-research [master's thesis]. Calgary (AB): University of Calgary, 1996.

370   Boyce W. Evaluating participation in community programs: an empowerment paradigm. The Canadian Journal of Program Evaluation, 1993; 8(1):89-102.

371   Comstock. Participatory research.

372   de Roux. Together against the computer.

373   Fals-Borda. Action and knowledge.

374   Florin P, Wandersman A.   An introduction to citizen participation, voluntary organizations, and community development: insights for empowerment through research.   American Journal of Community Psychology 1990; 18(1):41-54.

375   Goulet D.   Participation: The road to equity in development. Notes and Documents series of the International Institute for Labour Studies of the International Labour Office, Geneva, Switzerland, 1987.

376   Maguire. Doing participatory research.

377   Action research proposal for the evaluation and support of ongoing experiences with social participation in health development.   Division of Health Systems and Services, Pan American Health Organization/ World Health Organization, 1994.

378   Srinivasan. Options for educators.

379   Bopp M. The illusive essential: evaluating participation in non-formal education and community development processes. Convergence 1994; XXVII(1):89-102.

380   Fals-Borda. Action and knowledge; p. 62.

381   Gibbs L, Executive Director, Citizens Clearinghouse for Hazardous Waste, Cited in Florin. An introduction to citizen participation; p. 42

382   Bopp. The illusive essential.

383   Goulet. Participation.

384   Rahnema M. Participation. In: W Sachs, editor. The development
        dictionary: a guide to knowledge as power, pp 116-131. London:
        Zed Books, 1992:116-131.

385   Rifkin S, Muller F, Bichmann W. Primary health care: on
        measuring participation. Social Science and Medicine 1988;
        26(9):931-940.

386   Smith. Dancing with conflict.

387   Boyce. Evaluating participation.

388   Cohen J, Uphoff N. Participation's place in rural development:
        seeking clarity through specificity. World Development 1980;
        8:213-235.

389   Fals-Borda. Action and knowledge.

390   Freire. Pedagogy.

391   Arnstein S. Ladder of citizen participation. Journal of the
        American Institute of Planners 1969; 35:216-224.

392   Rifkin. Primary Health Care.

393   Goulet. Participation.

394   Farrant W. Addressing the contradictions: health promotion and
        community health action in the United Kingdom. International
        Journal of Health Services 1991; 21(3):423-439.

395   Grace V. The marketing of empowerment and the construction of
        the health consumer: a critique of health promotion.
        International Journal of Health Services 1991; 21(2):329-343.

396   Labonte R. Health promotion and empowerment: reflections on
        professional practice. Health Education Quarterly 1994; 21(2):253-
        268.

397   Werner D. Empowerment and health. Contact 1988; 102.

398   Hanson. Participation for transformation.

399   Goulet. Participation.

400   Jackson. Introduction.

401   Mduma. Appropriate technology.

402   Conchelos G, Jackson T. Participatory research for community education. Cited in: Comstock. Participatory research.

403   Tandon. Participatory research.

404   Barndt. Connecting immigrant workers.

405   Fals-Borda. Action and knowledge; p. 152.

406   Sanford N. A model for action research. In: Reason P, Rowan J, editors. Human inquiry: a sourcebook of new paradigm research. Toronto: John Wiley and Sons, 1981:173-182.

407   ibid.

408   Shields. Women's experiences.

409   Lindsey. Significant elements; p. 47.

410   Gerrard N, Javed N. A dialogue about racism and silence: personal and political perspectives. Canadian Woman Studies 1994; 14(2):64-67.

411   ibid.

412   Lord J, Hutchison P. The process of empowerment: implications for theory and practice. Canadian Journal of Community Mental Health 1993 12(1):5-21.

413   Kieffer. Citizen empowerment.

414   Labonte. #3 Health promotion.

415   Bain H. (1982). Community development: An approach to health care for Indians. Canadian Medical Association Journal 1982; 1(126).

416   Kuyek J. Fighting for hope. Quebec: Black Rose Books, 1990.

417   Cancian. Participatory research.

418   Maguire. Doing participatory research.

419   Labonte. #3 Health promotion; p. 59.

420   Arnstein. Ladder of citizen participation.

421   Labonte. #3 Health promotion; p. 65.

422   ibid; p. 68.

423   Guba. Effective evaluation.

424   Merriam. Case study research.

425   Lather. Issues of validity.

426   Denzin. The art and politics of interpretation.

427   Antovosky A. Health, stress, and coping. San Francisco: Jossey-Bass Publishers, 1979.

428   ibid.

429   ibid; p. 184.

430   Seligman. Helplessness.

431   Lewis O. The culture of poverty. Anthropological essays. New York: Random House, 1970:69. Cited in: Antonovosky. Health, stress, and coping.

432   Kohn ML. The interaction of social class and other factors in the etiology of schizophrenia. American Journal of Psychiatry 1976a; 133:177-180. Cited in: Antonovosky. Health, stress, and culture.

433   Lincoln YS, Guba E G. Naturalistic Inquiry. Newbury Park (CA): Sage, 1985.

434   Labonte,. #3 Health promotion.

435   Lather. Issues of validity.

436   Maguire. Doing participatory research.

437   Wallerstein. Powerlessness.

438   Brydon-Miller. Breaking down barriers.

439   Green. Control.

440   Maguire. Doing participatory research.

441   Brant Castellano. Aboriginal organizations.

442   Maguire. Challenges.

Gerri Dickson
June 1995

Sharing Our Health Circle:

The Grandmothers' Health Assessment Report

teachings
solutions
hopes
vision

concerns
of today

strengths in
our traditions

disruptions
influences

▲▼
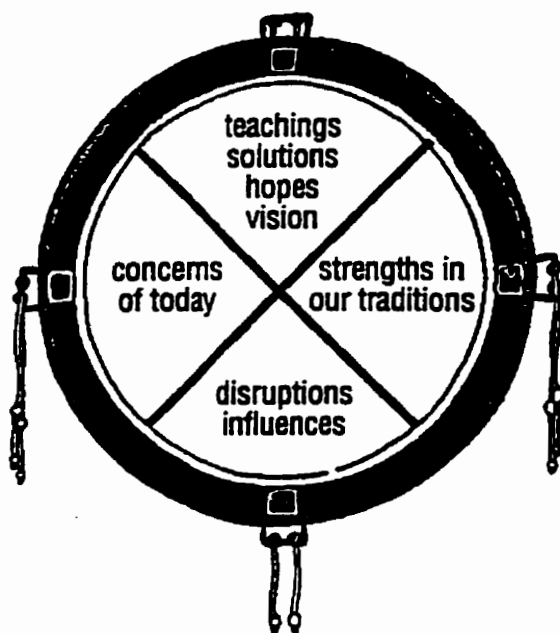
Introduction

We, the grandmothers of the Older Native Women's Health Project, describe our health in terms of our traditions; the disruptions that have occured in our lives; our concerns today; and our teachings and vision for improving the health and well-being of ourselves, our families, and our communities.

Each of us has lived a life different from each other. And we come from varied backgrounds: north-south, traditional-integrated, Treaty-Metis, Cree-Saultaux, first language English-First Nation. But we share our Aboriginal ancestry, our womanhood, our stage of life, our interest in our families, and our home in Saskatoon.

Our ideas on health were expressed on many different occasions: the weekly Tuesday morning group; home visits by the project staff; individual interviews with the research facilitators; focus groups; stories from our past; public consultations on poverty, and with the local Health District, City Council, and provincial Minister of Social Services.

This is not the usual type of needs assessment. Rather, it is the voice of the grandmothers on many issues related to health. We wanted to look as much at our strengths and resources as at our problems and concerns. So we renamed this a *health* assessment. And, we used *participatory action research* as the way to do the assessment. The grandmothers, staff, and research facilitator worked together closely for over two years to think about and describe our health.

The grandmothers have chosen the sacred tree to symbolize our belief in recurring life, hope, and the changing seasons. The tree represents the whole family - grandparents are the trunk, and the branches are the immediate and extended family. The grandmothers planted and blessed a tree on the grounds of Wanuskewin Heritage Park in 1993. The cover of this report shows the grandmothers behind their special tree.

> This report is written in the collective voice, with individual stories blended to form a group report. When one grandmother is describing something unique, this is noted by the use of "I" and a change in the style of print.

▲▼

▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽

Strengths in our Traditions

Good parts of our early life

When we were growing up, we had little money but we were self-sufficient for food and clothes, and we were happy. We grew up with our own people.

Life was very structured. People learned to do certain things at a certain time of the year for food and clothing. Everything was prepared in the summer for the winter. Dad worked in the fall, threshing, and made good money which was used through the year. Parents and family all gathered and did canning for the winter, so food was plentiful. We canned meat, berries, and vegetables, and also we dried meat, fish, and berries. In winter, people went to their camps and stayed till spring. We traveled by dog sleds and canoes.

The only things we remember our parents worrying about were us kids -- the girls getting pregnant and the boys being hurt in the army -- and family members drowning while hunting. The children were taught about survival in the bush and the possible accidents that can happen; we were cautioned in every possible way. For example, animals were used for direction when lost in a blizzard. Animals were valuable and sacred to our people.

In traditional culture, early pregnancies were not acceptable. The grandmothers influenced the young people and took the time and made the young people aware of taking care of themselves. Many marriages were arranged and most worked. Families were strong and kept in line. Whenever there was a problem in a family, an elder, priest, or minister would come in and talk to them.

A house without a woman is not a home.

People looked at women as attractive and as hard workers. They were seen as the nurturer in the family, the one who kept things together; they were respected for their abilities. Women had strengths in care-giving and housework. Jobs were shared by both husband and wife. Due to that, the children were brought up with discipline by both parents.

There were a lot of games played by all the family. We played cards in the evening after all our chores were done. Kids had a lot of time to play besides doing their assigned chores. There was no liquor (or hardly any) at that time. Life was busy and there was time for everything like prayer, work, and leisure. In the community, there were dances for weddings where everybody took part. Also, the people got together for Christmas in a home, for a simple but appreciated celebration, to pray and share traditional food.

In those days, we had no choice. If you wanted an education, you went to residential school. I learned the virtues of patience and tolerance. If I hadn't learned those, I don't know how I would have got through my life.

strengths
in our
traditions
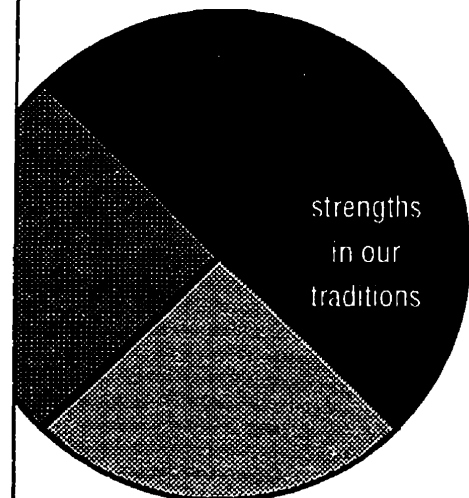
- *good parts of our early life*
- *our values and ceremonies*
- *our health*

310

1
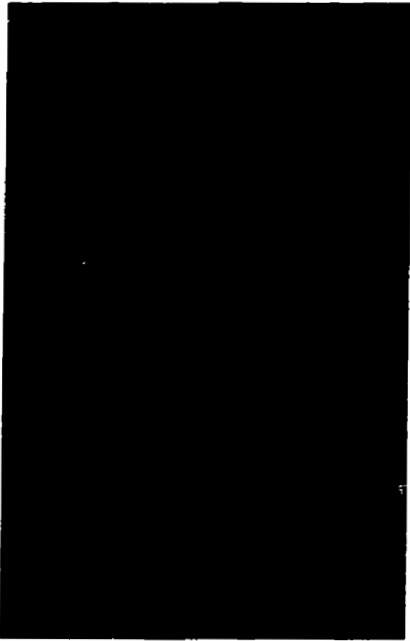
kisewatotatowin

"Back then I thought we were poor, but now I realize how rich we were."

"An elder is someone who is designated from early in life to be an elder . . . I was lucky enough to have three generations of teachers: my mother, my grandmother and my great-grandmother. I would sit at their feet and listen to their wisdom. They taught me the importance of love and respect."

Aboriginal people had a balanced, holistic view of health which included spiritual, emotional, intellectual, and physical health all in harmony.

We respected our environment. In the past, as now, some reserves never did allow motor boats on the lake. We always believed that would poison the fish. Today, people are concerned about pollution.

Our values and ceremonies

Our traditional strengths and values included: respect for our language; traditional spirituality; clear and respectful roles for women, men, seniors and elders, children; everyone as equals; strong family life -- kinship and love (no names were used, but "sister," "my girl," "my son," "uncle," etc.); everyone had basic information (therefore continuous questioning was not necessary); *kisewatotatowin* which means respect, obedience, love, kindness, humility, listening, generosity. There was less politics, (which is now seen in jealousy, control and power) because chiefs weren't elected. The oldest son took over from the father, or the chief was carefully chosen by the community if he proved himself worthy of being a leader.

Our own language is our culture. Through language, we understand and recognize ourselves.

Cree was a very important aspect of my life. I still like to talk in my Native language.

I am trying to bring back our culture -- sun dance, sweats, and the pipe. Mostly it was the old powerful men who had their own songs and spirits, from vision quests or dreams. From generation to generation, these were handed down. There were some powerful old women, too, who had a good spirit from the water.

My mother-in-law had a little pipe for her own ceremonies, with the smoke going to the Creator.

The family teaching is the way you set up the teepee -- every pole has a meaning, for example, respect, obedience, humility. Through lineage tracing, everyone was able to keep in touch with the ancestors. The teachings were lifelong.

When your child dances for the first time in a pow-wow, it is traditional to give away things such as blankets. When my daughter first danced, I was very proud. There is also a ceremony in which an elder can give you an Indian name. First you must find your elder, buy tobacco, a piece of material, and whatever you can afford, and give these to your elder. The elder prays to the spiritual grandfathers who tell the elder the name you should be given. This Indian name protects the person. The name could be Eagle, Bear, Raven, etc.

When a girl starts menstruating, there was a separate little teepee made for her. The grandmother was the one allowed in there, to teach the girl about womanhood -- everything -- how to make the hide, how to cook bannock, and about marriage and motherhood. For sex education, symbols and legends were used.

An elder is someone who is designated from early in life to be an elder; other older people can be a resource. I was lucky enough to have 3 generations of teachers; my mother, my grandmother and my great-grandmother. I would sit at their feet and listen to their wisdom. They taught me the importance of love and respect.

My mother did bead work and made quilts; she also tanned hides. She made moccasins for us and made an extra pair to give away to visitors or friends. Giving things away was an important tradition.

My mom taught us about the proper behaviour that was expected during celebrations. For example, if food was being prepared for a feast, we were not allowed to touch it. And at the feast, everyone sat down when the elder leading the ceremony sat down, and nobody was allowed to get up until he was done.

Our health

Aboriginal people had a balanced, holistic view of health which included spiritual, emotional, intellectual, and physical health all in harmony. The family and community prayed the Native way for good health.

In former days, there was little problem with cancer, diabetes, or high blood pressure because of the diet, activity, and few chemicals in Aboriginal people's foods.

My grandmother ate only our Native food. She never got ill, and if she did, she would use her medicine.

Our families believed that good meals kept us healthy. Traditional healthy foods were mostly wild or natural like wild meats, berries, vegetables, fish eggs in bannock, beaver tails. Everything was homemade. And the air was fresh in the country.

My mother used to say, if you eat too much it will disagree with you, which is abusing food, the same as everything else in life.

As a child our health was good; when ill, we were given rat root drink or other herbs. These were given to our parents by the medicine man/woman. Other times a medicine man/woman was approached, with a payment of tobacco, for treatment with natural herbs, prayer,

meditation with sweetgrass, and teaching on the Indian way of life. We had other home remedies like rubbing liniment on the chest or applying warm poultices.

Years ago, Native medicine was taken till a person got better, then it was only repeated if necessary.

I remember once when I got myself wet and cold and I had my period; I got really sick. My grandmother put me in a tent with a bed of hot rocks which she threw water on. She put a layer of twigs and a blanket and I laid down. Then she covered me with another blanket. She sat down beside me and burnt sweetgrass and prayed. She cured me.

At the first movement of the fetus in a pregnant woman, the midwife and other old ladies would put their hands on the mother's abdomen, and meditate and talk to her. They strongly believed the fetus could receive the message through the umbilical cord.

For the first 1 1/2 years, the baby was wrapped up and kept in a moss bag and swing for security and to teach the baby to use the other senses besides touch.

I remember seeing my mother prepare my infant siblings for bed. She would wrap them up in a waspison so that they would stay warm. She had a flexible twig that she inserted on either side of the baby's neck area. Over this twig she placed a cloth and tucked it in. The baby's own breath would keep him warm all night. The children were strong back then to have survived living in a tent when it was so cold.

When I was young, I was constipated a lot. My grandfather peeled the bark of a choke-cherry tree, boiled the bark, and gave me a drink of the water. For

toothaches, my grandfather used seneca root. When we'd get nosebleeds, he'd use sage leaves, roll them up, and put them in your nose. Yes, they worked.

When I had my period and was not feeling well, my mother-in-law boiled a tea and said the medicine would help me. She took a teaspoon and circled the cup of tea four times on top, talking of the meaning of life in this medicine prayer, and saying that one has to believe the higher power will put spirit into the medicine.

If the person got worse, the priest was called or they were taken to a hospital. The people did not suffer long from an illness years ago. They died in dignity. The suffering was not prolonged. Years ago, illness was accepted and acknowledged.

Disruptions and Influences in Our Lives

As a minority

I grew up Metis among richer French farmers and never learned to fight back. I was left with bitterness and an inferiority complex.

Those of us who are Treaty were "put in pastures (reserves) and couldn't eat the grass on the other side." People never owned anything, Indian Affairs did. Nothing was ever really yours, and we couldn't sell anything. Everything was branded "ID," Indian Department. Then they introduced welfare and we were worse off than before. There was no incentive to work in exchange for welfare so as to retain our precious pride and dignity.

"From the time I could walk until I was 6 years old I lived in moccasins. When I entered the residential school I got my first pair of shoes. That was the first step the White society took to rob me of my heritage."

disruptions
and
influences
in our lives
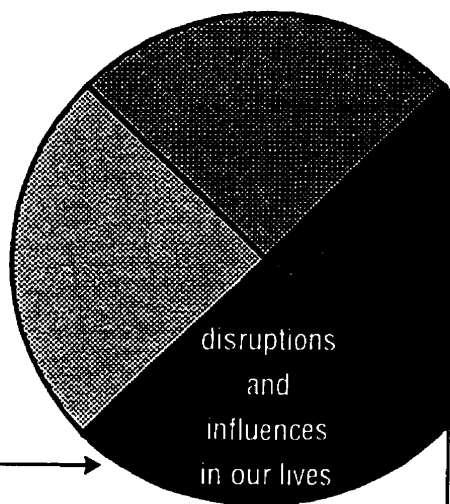
• **being a minority**
• **loss of our language**
• **changing roles**
• **family problems**
• **tuberculosis**
• **effects of war**
• **residential school**

Loss of our language

I had ignored my heritage. I was ashamed that I didn't know our Native language (we were never taught it) and that caused me the most shame. I could not join in the conversation and I would think that the others were talking and laughing about me. I stayed away from Aboriginals and I put on a big front for White society. I was caught in the middle and I didn't know where I belonged.

Changing roles

Women came to be thought of as below the men. Men came first, then women after. Women were thought of as child bearers only.

When we were moved onto reserves, men could no longer provide for their families, and they lost their traditional role and their self-respect. And with no jobs, some turned to alcohol.

Other family problems

My marriage was good in the beginning, but got worse over time. When my mother-in-law died, I adopted nine of her children. I had three children of my own and was pregnant with another. I washed all their clothes by hand, chopped wood, and hauled water. I got sick and the children were taken by Social Services because I couldn't take care of them anymore. Their ages were from 10 months old to 12 years old. The baby, Roseanne, never knew her mother. I missed them.

When I was 3 1/2 months old, my mother passed away. My aunt and uncle raised me. They were the only parents I ever knew. This mom never showed me any

love. All she had to do was keep her promise to my mother that she would raise me.

As I was growing up, I was sent to go and live with my auntie. When I was 13, I told my mom I wanted to come home. I don't know why they sent me to my auntie. My mom told me I was the crazy one in the family. Maybe that's why she gave me away. I always think it's better I don't know why. I have dreams about it. I still have problems with alcohol.

Tuberculosis

There were 13 of us children and we all survived childhood but not TB. Both my parents and all my siblings died from the disease. My mother was the first to die from it.

Effects of war

In our memory, our traditional way of life changed most when the boys came back from World War II. They had been introduced to drinking and there was more money, so the drinking increased. The soldiers would come to the dances drunk and take over. After the war, Aboriginal veterans were shunned by White society. They didn't get the same land compensation that White veterans did but the bars opened to them. They continued to drink to cope with the changes in their society and their experiences in war, which led to the problems of today.

Residential school

I was put together by others. I didn't know who I was, and had to re-educate myself about my Indianness.

I grew up in the North and was made to feel incompetent at school by nuns who

favored the White children. From this, I am left with fear and an inferiority complex from this failure.

At residential school, the nuns used to take off our clothes and scrub you hard between the legs, which hurt.

From the time I could walk until I was 6 years old I lived in moccasins. When I entered the residential school I got my first pair of shoes. That was the first step the White society took to rob me of my heritage.

I was 6 years old, and I remember that Sister yelling at me, "You, quit speaking Cree and being a savage!" The school was very strict. I couldn't speak my own language. And they cut my hair so I could look like a "human being." Life at the residence was very degrading, but I survived and so did my values and beliefs. I was there for 10 years. The only time I could go home was when there were weddings or funerals, and even then it was only for the day. On Sundays, parents who lived near the school could come and visit their children.

When I went home for the summer, my world was reversed again. I could only speak Cree because my mother couldn't understand English. Being in the residence had made me take life's basic necessities for granted. Now I was back to hauling water, chopping wood, and using outside toilets. It seemed that I would regain my traditional way of living only to go back to the residence and forget it for another 10 months.

When I was 14 years old I was diagnosed with TB. A priest took me to the Prince Albert Sanitorium. I was admitted November 14, 1949. I was there until April 12, 1952. I wasn't allowed to go home once. When I was discharged I didn't want to leave. This had been my home and I thought of it as

home. I would cry all the time because I missed my friends. My Mom would tell me, "Don't cry, you're home now," but I hated the reserve.

I was 17 years old and had been home for 10 months when my Mom passed away. My mother was a medicine woman. She worked with herbs and I remember going with her to gather them. She had three daughters she tried to teach, but we had no patience for it. The knowledge died with her and now I deeply regret that loss. She never received any payment for her services because that was how she wanted it. She said that she did it out of love for the people.

I don't believe there was ever any intention to educate Indian children in those residences. We would only go to school for half a day, and the rest of the time we were working. The girls did the domestic work and the boys took care of the farm work. It was a hard life.

I was a boarding school product. I went home every two to three years. I got to hate the nuns, priests, and brothers for physically abusing me. They used to tie me up on steel bunk beds and strap us or take us to a barn to whip us. I was in boarding school at age 3 years till 16.

"The school was very strict. I couldn't speak my own language and they cut my hair so I could look like a "human being."

"I grew up in the North and was made to feel incompetent at school by nuns who favored the White children. From this, I am left with fear and an inferiority complex from this failure."

"There were 13 of us children and we all survived childhood but not TB. Both my parents and all my siblings died from the disease. My mother was the first to die from it."

5

In some cases, seniors are abused.

We did not go wrong as parents -- there's something else wrong in kids' lives.

Social and economic

Most Aboriginal people have an inferiority complex. It never leaves you 100% -- you always have the feeling at the back of your mind that you are not good enough, and you always have to fight this.

When we moved to the city 30 years ago, we felt as if everyone was watching us. There is also fear -- am I going to say what I really feel, or will that bring rejection? We see racism in our daily lives.

Many Aboriginals are left with bitterness and an inferiority complex because of the way we are treated by others. Many take alcohol and drugs to compensate.

▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽

Many Aboriginals are left with bitterness and an inferiority complex because of the way they are treated by others. Many take alcohol and drugs to compensate.

▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽

Today, in the city, there is much poverty and family break-ups, with abuse.

If you have $20, there is not much you can do with it, so you might as well play bingo and try to get the almighty dollar.

Sometimes people are turned down for jobs because of being Aboriginal.

People get discouraged when they can't live like others, yet they don't have the education on how to live. But if mom is at bingo, she doesn't have time to teach the children. So lack of knowledge is a problem.

The causes of poverty include: lack of education and job skills; job training that goes nowhere; single-parent homes; lack of awareness of resources available to us; language barrier; domination by mainstream Canadian society; loss of self-esteem and dignity; lack of knowledge on how to budget; gambling, bingos, lotteries -- addictions; hierarchy, capitalism; loss of identity and culture -- and denial of this.

Many Aboriginal people in the city live in poverty. The effects of this are alcoholism; drug abuse; gambling; prostitution; unplanned pregnancy; large

316

▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽▲▽

family size (people mistakenly believe the more children they have the more money they'll receive); loss of self-esteem and dignity; being too proud; crime; not attending school; drop-outs; family break-up (affects children even if parents don't realize it); people in poverty not wanted in community because of their alcoholism, etc. and others tend to stay away from them, leading to feelings of rejection and isolation, which lead to a divided community; child and wife abuse; accidents; poor housing conditions; sickness; lack of nutrition; little/no participation in sports; hopelessness -- might as well stay drunk; suicide.

Besides poverty, we are also concerned about the kids. Kids are now showing more aggression when referred to as "Native" by others and this is a concern for us. We worry about children in the streets. It really hurts to see young people in courtrooms pleading guilty for any crime. Going to court is almost a game. Now young people don't learn the basics of life skills.

Young girls are having babies at age 13 and 14. The reason for pregnancy might be due to financial problems -- teens have no jobs. We must look at the root causes of teen pregnancy -- young mothers are not the problem. We should look back to the family which may not be strong enough, and then the family shows no love or caring for the children. Many young people are sexually and physically abused. And society and the media give them critical messages. All this leads to low self-esteem, and leads to more early pregnancies.

We are concerned about a lot of single parents. Divorce causes confusion. Families are no longer united. A single mother who has no child care can't even go to events for the family. It creates so much stress on parents to be both a parent and to work outside the home.

respect the Aboriginal spiritual values and traditions.

A patient in the hospital needed an elder, and a new nurse didn't understand the use of meditation and sweet grass. Another patient was wearing [an amulet of sacred] protection. This was taken by a nurse, opened up and spoiled.

Aboriginal people come as a group for hospital visitation, which is a problem in some hospitals, but visitors come from out of town.

I was visiting my son in the hospital almost daily. An old Aboriginal lady in the other bed couldn't speak much English. She wasn't treated like the other patients. The nurses made fun of her stomach problems, but she couldn't eat because she missed her Native foods. She wanted to go home but couldn't communicate this.

Some people have to sneak in Indian medicine or tonics for their relatives to use in the hospital, which is not the way it should be. People are afraid to talk to the doctor about using both traditional and Western medicine.

There was a meeting one of us was invited to in which some doctors wanted to know from us how to mix certain traditional herbs. The doctors didn't understand that we can't even talk about it. This is only for the special medicine person who was gifted and taught how to use these whenever they were approached in the right way with great respect.

Many of us have diabetes, some have arthritis. Other common problems are high blood pressure, heart disease, kidney disease, lack of bladder control, difficulty moving around.

Many of us are overweight, and we don't seem to do anything about it, even though we know it brings on other diseases. However, some of us don't have enough money to change our diet to eat more fresh fruits and vegetables.

I am afraid of the long-term effects of uncontrolled diabetes such as blindness, because I'm having trouble controlling my blood sugars.

Some diabetic family members are not compliant with instructions given by us – they'll only listen to the professionals.

My food often goes to my grandchildren.

I am out of my diabetic medicine, but I missed my medical appointment yesterday because I had to baby-sit my grandchildren.

I'm afraid of seeing a doctor in case there's bad news or surgery needed. My previous problem has come back

since my last surgery but I'm afraid to find out more.

Some of us have distressing things such as hot flashes and sleeplessness, as we get to menopause.

Some disabled people are treated almost as if they are not there; for example, a man with no legs has no wheelchair. He needs to be connected with the Abilities Council.

Among us, we rate our own health anywhere from poor to excellent.

Health care system

For those of us with chronic diseases, it's too expensive to try out various costly medications in an effort to find one that works.

What's in the pills that the doctor prescribes? We don't know what all the pills are for.

Aboriginal people have more diabetes, but St. Paul's Hospital has cut out its diabetic education.

Hospital staff don't know and don't

I had to wait 2 months for an appointment with a specialist, then I waited a long time in his office, and then he only spent 3 minutes with me. He doesn't give you time to talk or ask questions. I should say,

"Doctor, just a minute. I'm not finished yet!" We should learn to say that, really, and "Sit down and listen!"

It's confusing in the city with referrals to different offices for tests and doctors.

There are ones that aren't able to get out, particularly the elderly, and have no means of transportation, and can't get to the doctor. Why can't the doctor come to us in this case?

Working with Sherbrooke Community Centre, our main concern is disabled and old people without the right services. Each of us older women may need these facilities at some time. Our other concern is lack of nursing home jobs for Aboriginal people. Reserves have health clinics but not enough long-term facilities or services. And very few Aboriginal people have home care. We can't get home care services because of the costs, even though we need it.

"The health care system now is not working for Aboriginal people. They don't understand our needs. We have not been met half-way over the last hundred years, and it's time for White society to compromise."

"We want to be independent, even in our old age, but we want a health care system we can call on when needed."

Other services and institutions

In consultations with the Provincial Minister of Social Services, we, the grandmothers, highlighted the following concerns about social assistance:

- transportation: there is no allowance, which poses a hardship, especially for elderly, sick seniors, and when trying to get to welfare and health appointments;
- child apprehensions: the Department doesn't warn families and work with them enough to prevent apprehensions. Social workers aren't trusted because they take the children away. The family is not supported enough so that the children can stay with them;
- foster care: child rearing is done differently in White homes; there aren't enough Aboriginal foster homes; there are different rates for foster parents, with those in the city getting more than on the reserve; when the grandmother looks after her grandchildren, we don't get enough support to care for them;
- special diets, for example, for diabetes, renal failure patients: the special allowance based on a caloric diet is not enough for the fruit, vegetables, protein, etc. needed;
- housing damage deposit: it needs to be given for each new housing because landlords do not refund it. Rather, they call normal wear and tear "damage" and keep the deposit, so tenants pay deposit for new housing out of food money;
- moving expenses: 3 estimates are needed which is unrealistic, often, for unwell seniors with no transportation to secure these estimates;
- respite costs for a dependent son at Parkridge: Social Services argues that one of the grandmothers should pay the $25/day for him because they continue her monthly cheque for him; however, she only receives $23/day, and yet she has to keep up apartment costs on his behalf even if he's not there;
- social workers need to remember why they went into social work, and have a better attitude with the people, even when their work load is heavy. A lot of social workers, and other professionals, still carry pain and hurt from their own experiences so, in turn, they don't feel good about the people they're working with;
- a lot of Aboriginal people don't speak up for themselves, so other people don't know how bad it really is.

Other related Social Services concerns: their appeal board treats you as if the money comes from their own pocket; "If I could work I would. I don't like this at all;"

I'm asked to fill out a job search form, but I'm too old; one month a cheque stopped because there were too many people living in my house -- a lot of our relationships are like that, that is, living with someone, it's Aboriginal tradition, but this is not OK with Social Services; they say you can't live with someone, but this breaks up the family -- "My son needs a man in the house"; the poverty line is above what you get from Social Services; there are identical concerns with poor White people.

SADAC no longer has programs for young people like they did at the old Calder Centre in St. Paul's. There used to be both a 3-week inpatient education program and one for a week over Easter and a month over summer, and these were cut out. These are needed.

Some AA programs are not fitting for some Aboriginal people - facilitators use high words in some of the programs; Aboriginal participants can't understand. This applies to other programs, too. But other Aboriginal people have stopped drinking with AA.

children's workshop for Aboriginal cultural crafts so they learn about their traditions and values. Children should have to be taught about our Indianness. It's important to be aware of who you are and what is your culture. Aboriginal languages should be taught in the schools.

▲▼▲▼▲▼▲▼▲▼▲▼▲▼▲▼▲▼▲▼

Our Teachings, Solutions, Hopes, Vision

Re-searching our traditions

We can't go back, but we can carry on our beliefs, values, and traditions. We almost lost them, there was a weak spot. But now they're coming back again. Our youth are so lost because their parents lost their role. Now even White university students come to us asking if there's anything in the Indian way to relieve pressure. We tell them to use sweetgrass and meditate in their own way -- go out walking, into nature, open their mind, and talk. Our traditions are coming back.

My auntie, who still followed the traditional ways, made me understand that I had to connect with my Indian identity in order to move forward. When I started to learn about my traditions and started

to know myself at a deeper level, then the healing began. I have come to the conclusion that happiness has to come from within yourself. It's so important to teach and understand the inner feelings of human beings. Once you know who you are, you become a very strong person, and this makes it easier to help the next

person. My happiness is no longer dependent on the happiness of others.

I turned from alcoholism and being a victim of violence to sobriety by going back to my traditions, starting with a sweat. I was not to go into the sweat for 4 days after taking alcohol. But I was smudged a lot to allow me to enter within 24 hours because of the urgent need to change my life. After 4 rounds in the sweat, I felt light and strong. I've been sober ever since. I follow much tradition -- fasting, sweats, medicines. I pray to the Creator directly from the heart.

I have a strong feeling when I smell sweetgrass -- that's what gives us strength.

The speaking rock is a spiritual rock and can help us heal. Trees and grass are all medicine to use in a good way.

As grandmothers, we need to be educators for young people today.

The time is here when our children and grandchildren have to know who they are, where they belong, and what their culture is. We have to cling to our heritage. Parents should talk and teach the Native language at home. We need a

Will is not as strong today, so the development of will is important. For many to develop will, reinforcement and support from one another is important.

our
teachings . . .
solutions . . .
hopes . . .
vision
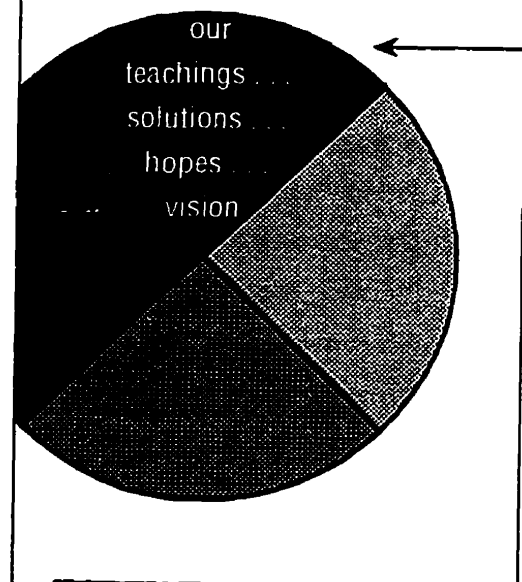
• re-searching our traditions
• personal development and self-care
• support one another
• health care system
• other services

White society has to understand Native culture and it's time to speak up about this.

help mental health. Through these, you learn to love yourself. Then you can express love to others and be comfortable about it.

- Crying is good sometimes. You can't always be strong. You have to solve problems by talking about our own problems, by trusting others. From Al Anon, I learned to let go.

- I've learned assertiveness, to say no. It hurts because my dad never said "no" to anyone. It hits your feelings, yet in the head you know you're doing the right thing. It was hard at first, but it doesn't bother me now. I can say "no" to friends, asking me to go to bingo; to my husband so I don't become a slave; to my son asking for money. Now, my children know what to expect. It feels good. Nobody else will stand up for me if I don't.

- Sometimes we get a wrong bill for something, or we don't get a service we should be getting. As grandmothers, we have to speak up for what we don't think is right. It's the idea of it. We have to put it in writing, and send in a letter.

- Keep busy to forget sickness. I can cope with my arthritis because I learned from my parents how to make the best of life. When I hurt, I don't sit and whine, I do something. I get involved with the community. I go on an outing for a few hours. I think of other people who have other diseases and then I feel there's no reason to sit and feel sorry for myself. But I have to limit what I try to do. And laughter is good medicine. And I go to church.

- For us as women, no matter how old we are, we should all go for mammograms.

- We must get proper food and sleep. We try to eat our Native foods. There is a lot of interest in Native foods for health today.

- I use the Western medical system. And I use some traditional medicine depending on what's the matter because it helps me feel better, lighter. When I can't shake the feelings of arthritis, I burn sage, sweetgrass, or tobacco, and it settles me down and I don't feel the aches and pains as much.

"Doctors should put more on house visits. Maybe the doctor should make an effort to make a home visit."

"I had a real good doctor at the Community Clinic who, rather than give me pills, would send me to a counsellor to talk my ideas out. He never just prescribed. If he sensed that you were having inner problems with yourself, he'd send you to a counsellor. And that was the best thing that he could have done for me, 'cause I'd be a drug addict today if it wasn't for that. I know a couple of doctors who recommend those tranquilizers to solve your problems. But it doesn't solve your problems. It makes it worse."

Support one another

White people have to approach the Aboriginal people differently, not as different. They are always looking at Aboriginal people as different. We are not different – we have the same feelings and needs.

We see the importance of spending time with each other to listen and understand, as was done traditionally.

This project is something people will understand – uniqueness, values we share, joy we bring to peoples' lives. We'd like to see it go on year after year. The circle is getting stronger. It's a good support. It's good to talk and laugh at the beginning of our weekly morning group. Many older people don't have this opportunity. In our healing circle, it's good to bring out the pain slowly. I'm learning to trust because everything stays in the group.

Health care system

White society has to understand Aboriginal culture and it's time to speak up about this. The health care system staff – doctors, nurses, home care staff, and others – need to understand Aboriginal people. They need orientation regarding our traditions, values, and culture. They need to work on the language barrier – medical jargon, understanding medications, and translating into our own Native languages. We want clear and simple language. And the health professionals need their own personal human development work so that they can work well with us.

We are independent and it's a good thing. Not many of us are in nursing homes. We grew up self-reliant and want to take care of ourselves. But don't feel ashamed if you're disabled and have to go into a home and be cared for by others.

People doing research with Aboriginal people need to be more sensitive, and do research with the people, like this project is doing.

The Saskatoon District Health Board can learn from Aboriginal people's balanced holistic view of health, which includes spiritual, emotional, intellectual, and physical health all in harmony. The health system needs Aboriginal staff for us to contact so that we know how and where to get the services we need. We need trained Aboriginal field workers to reach out to our people. We need more, accessible diabetic education, translated into our languages, so Aboriginal people understand the disease. And we need dietitians to teach this so that diabetics follow a good diet. We must work now to make things better for our children and grandchildren who are our future leaders. It is time to take back control and do our own thing. Aboriginal people want to do their own thinking and quit being treated like children.

Aboriginal people as nations want a partnership relationship with the Health Board, with an active steering committee and representation on the Health Board, guided by our elders. We want the health care system "to walk the talk," to hold the values of *kisewatotatowin*, to recognize that health is a treaty right, to work for better understanding.

Sherbrooke Community Centre's Aboriginal consultations need to lead to better support of disabled people, and equal representation of jobs and training for Aboriginal people. It is important for us, the grandmothers, to speak up because many institutions are now asking for our opinions.

The grandmothers support the Community Health Unit's street outreach/ needle exchange program. Their street workers help prevent AIDS, but are also there for kids who are looking for that special feeling of love. *I grew up in Vancouver, and was looking for love with that behaviour on the street.*

We need a lot of education to go with prevention. There were a few years there that people saw how that boy deteriorated with AIDS. Now that memory is slowly fading away, until AIDS erupts again.

I had a real good doctor at the Community Clinic, who, rather than give me pills, would send me to a counsellor to talk my ideas out. But he never prescribed. If he sensed that you were having inner problems with yourself, he'd send you to a counsellor. And that was the best thing that he could have done for me, 'cause I'd be a drug addict today if it wasn't for that. I know a couple of doctors who recommend those tranquilizers to solve your problems. But it doesn't solve your problems. It makes it worse.

Doctors should put more on house visits. Maybe the doctor should make an effort to make a home visit. We remember the doctors at the Community Clinic who used to come out, and that's why a lot of people liked the Clinic.

They're increasing the budget for home care. But if we are to keep our loved ones at home, we need a good assessment and enough resources from home care so there's no neglect. But also, we need things like space in the home with widened doorways for wheelchairs, bars and bathtub lifts, built-up toilets, etc. And the caregiver needs to be in good health and needs to have enough training, support, and respite to take this on.
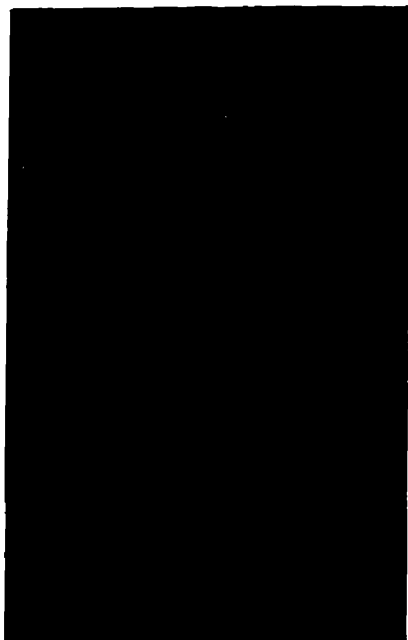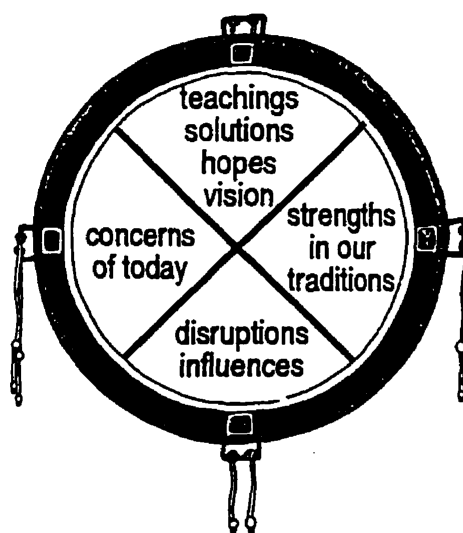
before it happens, the family should be warned, the situation should be investigated, and the one who complained checked out. Most importantly, more work needs to be done to keep the family together. If the grandmother is healthy and able to care for the grandchildren, some of us would rather see them come to the grandmother's home, than be placed elsewhere. We can start over from the mother. We loved our own children, but we have more love available now for our grandchildren. All we want is enough resources coming to our own home to care for our grandchildren. But if the grandmother is not feeling well enough, she can't give good care. Other extended family should be looked to first to take the children, rather than placement in foster care elsewhere. Foster home rates must be the same on the reserve as in the city. Regarding the housing damage

deposit, we can give our support to the Riversdale Neighborhood Association and West Side Community Clinic who are working on a tenants' rights lobby group to stand up to the landlords. And the way that social workers treat clients needs to improve. To do this, the workers need personal development programs to heal their own pain and hurt.

Things we feel most strongly about include: anything that hurts kids, stopping casinos and gambling, a desire to return to traditional foods, and respecting and saving our environment - all for the health and safety of our future generations.

We close this report with the image of the sacred tree, our health circle, and the word, *kisewatotatowin*, all of which have special meaning for us and our project.

"Things we feel most strongly about include anything that hurts kids, stopping casinos and gambling, a desire to return to traditional foods, and respecting and saving our environment - all for the health and safety of our future generations."

teachings
solutions
hopes
vision

concerns
of today

strengths
in our
traditions

disruptions
influences

kisewatotatowin

March workshop (one day)

- an introductory Aboriginal video, "Healing ourselves, healing our communities"
- information from staff to the advisory committee about project activities and grandmothers' participation
- PAR origins, definition, uses, stages, examples
- comparison between PAR and conventional research
- terms of agreement and consent; aspects of life in which empowerment may be assessed, and what these aspects would look like if change occurred
- methods to record what the research would learn

June workshop (half day)

- health assessment in relation to the goals of the project
- health assessment research design
- proposing individual interviews with advisory committee members based on the empowerment framework developed at the last workshop
- assumptions held about the research topic
- research activities' time line
- summer community listening survey.

October workshop (two days)

- the medicine wheel/sacred circle• review purposes of a health assessment
- research design from work done at previous workshops
- other purposes of our health assessment (besides the principal motive of empowering the participants) for upcoming briefs and securing ongoing project funding
- possibility of training funds for research associates to assist with the health assessment
- community listening survey
- review of and response to the findings of a related provincial study of unmet needs of off-reserve Indian and Metis elderly
- summary of existing data and desired new data
- advisory committee members invited to assist with other aspects of project.

Gerri Dickson: Summer. 1993

Community   Listening   Survey
for   Health   Needs   and   Strengths
of   Older   Aboriginal   Women

survey method:
- listen with a clear idea of what you are listening for
- listen to unstructured conversations--when people are relaxed and talking about things of most concern
- listen for the issues about which people have the strongest feelings -- *emotion* is linked to *motiv*ation
  only on issues about which they have strong feelings will people be prepared to act
- what are people worried about? happy about? sad about? angry about? fearful about? hopeful about?

survey team: staff, advisory committee, and community grandmothers of the project

listening situations: The team must find ways to listen to spontaneous discussion of the community without manipulating or embarrassing anyone. Where appropriate, it is good for the community people to know that the team is doing a health needs assessment and that they give their full and conscious cooperation.

Places to listen include: shops and grocery stores; buses; laundromats; homes; bingo halls; food banks; social services; bars; etc.

note: The term *grandmother* is used for all older Native/Aboriginal women 45 years of age and older, residing in Saskatoon.

areas of life about the grandmothers' community to cover in the listening survey

1.   **meeting basic needs**: food, clothing, housing, water, sewer, health and health care

2.   **relationships between people**: social relationships (tension or harmony) between men and women, husbands and wives, parents and children and grandchildren, employees and employers, leaders and community members

3.   **community decision-making processes and structures**: what are the structures for involving people in decisions? what are the rules of the group? who makes them? who enforces them? does power depend on age, family, reserve, tribe, position, knowledge, money, education? how do people feel both about the decisions that are made which affect their lives, and the way the decisions are made?

4.   **education & socialization**: both through schooling and traditional education, people are taught values, skills, and acceptable ways of behaving as members of a community; what are these? what do people learn and do about a birth, marriage, death and funeral, raising children and discipline, respect for elders, teaching of traditions? are there changes taking place? what tensions occur through these changes?

5.   **recreation**: what do people do to relax and enjoy themselves--play or watch sports and games, play bingo, visit and talk, sit and rest in silence, sleep, do creative art or craft work?

6.   **beliefs & values**: all groups have a basic set of beliefs through which they express their understanding of human life, death, the world, love of God, etc.; with these beliefs and values people decide what is important in life; what are these?

things to understand about each area

a)   **what** people do? **who** does what? are **customs** changing? are **expectations** of what different people ought to do changing?

b)   **why** do people do what they do (the economic, political, and cultural reasons)?

c)   what **issues** in each of these areas of life arouse **emotional interest** at present?

d)   which are the most important and frequent **words** used on these issues?

areas of health of the grandmothers to cover in a listening survey

1.   **specific information**: how many grandmothers are there in Saskatoon? where did they come from? if they moved to town, why? what ages are they? what is their financial state?

2.   **language and culture**: what are the grandmothers' first languages? what are their values and beliefs related to health? what knowledge do they have about traditions? who practices a traditional way of life? who practices traditions in the city? who makes decisions about them? what do they do for fun and recreation?

3.   **social relationships**: what and how are the relationships in the city with family? with friends? with the community at large? with the local and Aboriginal leaders?

4.   **concept of health**: what do the grandmothers mean by "health" and "disease"? what do they believe leads to good health? what leads to ill health? what is their sense of power and control over their health and health care?

5.   **health status**: how would the grandmothers describe their own health status--poor, fair, good, excellent? what are their health problems?

328

how many grandmothers are physically handicapped? what diseases do the grandmothers have?

6.   **health practices**: what do the grandmothers do for self- care? what do they do for their health and well-being that is based on tradition? based on western learning? what are the spiritual practices? how do these relate to health?

7.   **health services**: where do the grandmothers go for services-- western? traditional? what kind of services do they use and why? what do the grandmothers know about the different levels and systems--federal, provincial, municipal, self-government?

8.   **society in general**: what are society's attitudes about Aboriginal people? in the city? how do society's "isms" affect the grandmothers-- institutionalism, racism, classism, sexism, judgementalism? what are western professionals' attitudes to healing?   what are the western systemic rules and regulations about health?

9.   **issues**: what do the grandmothers say are their greatest worries? what are the most emotional issues? which do they have the greatest desire to do something about?

10.   **strengths**: what do the grandmothers say are their strengths? what do others see as their strengths? what are examples of contributions to family and community life by grandmothers?

Guide for Interviews with Participants of the Grandmothers' Project on their Past Strengths

The purpose of this research is to contribute to the *kohkoms'*[1] empowerment, to give them back respect and control, and to restore confidence and pride, to help build a community of *kohkoms*, give them a voice and opportunities for leadership, bring back their roles. We are doing this by more listening, asking, and giving opportunity for the *kohkoms* to see their own strengths and for being a friend. We are searching out information about the way it was, the way it is, and the way it ought to be, continuously reflecting this back to the *kohkoms*, and taking action on their concerns.

Consent:
- explain project; clarify we are not government
- words will be shared with other grandmothers and for the health assessment report, and perhaps as part of a voice of the grandmothers for public purposes eg. City Council, Saskatoon Health Board
- but anonymous (no names) and confidential (private)
- participation is voluntary and may decline any time
- time: interview takes 1 - 2 hours

Critical analysis, probing questions for strengths
Naming the strength
What was the strength?
Was it strength of the heart, of the will, and/or coping skills?

Reflecting
Why were things as they were?
How were you/others able to have this strength?
Who/what helped you/others gain this strength?
What kinds of things did you/others do to help this situation?

Acting
How did you/others use the strengths to change things?
What should be done using the strengths?
What will be done?

1.   Let's talk about when you were young
  a)   Where did you grow up?
  b)   Is this where your parents were from?
         Is this where your grandparents were from?
  c)   What brothers and sisters did you have?
  d)   When you were growing up, what languages did you speak?
  e)   What did you do for schooling?
  f)   When you were young, what were your experiences with
         other people?--White, Metis/Indian, other ethnic groups
  g)   What were your parents most worried about back then?

---

[1] *Kohkom* is the popularly used term for the Cree word for grandmother.

2.   When you were young, what kinds of things did you do for fun? What were the good times?
(probing) • Think back to when you were a very young child, what were some of the happy times with your family/ in your community?
                        • Can you tell me more about that?

3.   When you were young, what kinds of beadwork and sewing did your grandmother and mother do?
a)   who taught you?
b)   how did she/he teach you?
c)   what kinds of things did you make (eg jewelry, mocassins, mukluks, hightops, jackets, clothes, mitts, gloves, knitting, rugs, embroidery)
d)   what kinds of designs did you use? (eg. flowers, animals, geometric shapes)
e)   when you, your mother, your grandmother did your beadwork and sewing, did you keep them, sell them, give them as gifts?

4.   When you were a child, how was your health?
a)   what did your family and community do to keep themselves healthy? (eg. diet, outdoor activities)
b)   What did your family believe kept people healthy (show & explain medicine wheel)
b)   what did your family do when someone got sick?
(i)   traditional treatment: who, what kind of medicines, did the treatment work?
(ii) western treatment: who, what kind of medicines, did the medicines work?

5.   What did you learn from your parents and grandparents about living off the land? regarding:
a)   hunting, fishing, trapping, gathering
b)   shelter
c)   safety (eg. ice, guns, wild animals)

6.   When you were young, what kind of religion did you practice?
(i)   traditional - beliefs, practices
(ii)   Christianity - beliefs, practices

7.   Tell me about your life when you got married; what was the date?

8.   How do you think women were thought of in those days
(i)   by the family
(ii)   by the community
What were women's strengths?

closing:
• reflect back the strengths heard in the responses
• next visit, present strengths
• thanks

Gerri Dickson 1993-4

Guide for Interviews with Participants of the Grandmothers' Project on their Present Strengths

The purpose of this research is to contribute to the *kohkoms'*[1] empowerment, to give them back respect, and control, and to restore confidence and pride, to help build a community of *kohkoms*, give them a voice and opportunities for leadership, bring back their roles. We are doing this by more listening, asking, and giving opportunity for the *kohkoms* to see their own strengths and for being a friend. We are searching out information about the way it was, the way it is, and the way it ought to be, continuously reflecting this back to the *kohkoms*, and taking action on their concerns.

Consent:
- explain project; clarify not government
- words will be shared with other grandmothers and for the health assessment report, and perhaps as part of a voice of the grandmothers for public purposes eg. City Council, Saskatoon Health Board
- but anonymous (no names) and confidential (private)
- participation is voluntary and may decline any time
- time: interview takes 1 - 2 hours

Interviewer:
- looks for: kohkoms' personal hygiene, dress, body language; surroundings - cleanliness, state of home, neighborhood, "camping"
- listens for - special interest for specific attachment to community schools, Sherbrooke, Joe Duquette; words the kohkoms use to describe themselves, events, etc.

Critical analysis, probing questions for strengths
Naming the strength
What is the strength?
Is it strength of the heart, of the will, and/or coping skills?
Reflecting
Why are things as they are?
How are you able to have this strength?
Who/what helped you gain this strength?
What kinds of things do you do to help this situation?
Acting
How are you going to use your strengths to change things?
What should be done using your strengths?
What have you done?
What will be done?

1.   What kinds of fun things do you do for a pastime?
  a) at home .... out of home
  b) in the city .... back home (if appropriate)

---

[1] *Kohkom* is the popularly used term for the Cree word for grandmother.

2. When you have your fun times, whom do you do these with?
   a) family .... grandchildren .... friends .....community ...... self
   b) when and how often do you do these fun things?
   c) tell me how you feel when you're doing these things
   d) who is the most important person in your life right now?

3. Do you do beadwork, sewing, or crafts now?
   a) what do you do with your crafts, etc. - keep them, sell them, give them as gifts?
   b) do you still practise cultural gift-giving for visitors? if so, tell me about it.

4. What language(s) do you speak?
   a) how did you learn the language(s)? who taught you?
   b) do you still use the language?
   c) do you teach it and to whom?

5. a) What do you do to keep yourself healthy today/now a days?
      (i) traditional - beliefs, practices
      (ii) western - beliefs, practices
   b) What do you do when you or your family gets sick?
      (i) traditional - beliefs, practices
      (ii) western - beliefs, practices
   c) Where and how did you learn to
      (i) keep yourself healthy?
      (ii) cope with your illness?

6. Think about and tell me about times when you said "no" to a family member, friend, or other (give examples). How did you feel when you did say "no"?

7. a) When you want to go someplace, how do you get there? in the city, out of the city
   b) How did you come to live in this place? how long have you been here? How do you manage here? Who works with you?
   c) What kinds of payments do you make? How do you manage?

8. If you had the opportunity, what would you teach the younger people? Tell me about how you teach. Give me examples.

9. How do you think women are thought of/looked at these days/ today? by the family, community?
   a) What are the strengths of women today, young and old?

10. What agencies or programs are working with you now? What services are you receiving from them? What help does this give you?

closing:
   • reflect back the strengths heard in the responses
   • next visit, present strengths
   • thank you

333

Gerri Dickson 1993-4

<u>Guide for Interviews with Participants of the Grandmothers' Project on their
Problems, Issues, Concerns Interview Guide</u>

The purpose of this research is to contribute to the *kohkoms*'[1] empowerment,
to give them back respect, and control, and to restore confidence and pride,
to help build a community of *kohkoms*, give them a voice and opportunities
for leadership, bring back their roles.   We are doing this by more listening,
asking, and giving opportunity for the *kohkoms* to see their own strengths
and for being a friend.   We are searching out information about the way it
was, the way it is, and the way it ought to be, continuously reflecting this
back to the *kohkoms*, and taking action on their concerns.

<u>Consent</u>:
• explain project; clarify not government
• words will be shared with other grandmothers and for the health
  assessment report, and perhaps as part of a voice of the
  grandmothers for public purposes eg. City Council, Saskatoon Health
  Board
• but anonymous (no names) and confidential (private)
• participation is voluntary and may decline any time
• time: interview takes 1 - 2 hours

<u>Critical analysis, probing questions for strengths</u>

Naming the strength
What is the problem?
Should things be as they are?
Is this how it ought to be?

Reflecting
Why are things as they are?
Who/what is to blame?
What is your role in this situation?

Acting
What can be done to change things?
What should be done (self and others)
What have you done?
What will be done?

(ask Cree words for: needs assessment, strengths, health)

<u>strengths</u> heard in previous interviews = coping eg. budgetting, grief,
change, family stress; the way of learning is from each other; importance of
language and culture; cooperation; organizational skills, eg. managing a
family at a very young age; values most important - kiseywatotatowin,

---

[1] *Kohkom* is the popularly used term for the Cree word for grandmother.

sharing, caring, respect; being more assertive, speaking up   REFLECT
BACK

problems = to what do the grandmothers most urgently need to apply these strengths/qualities and skills? What partnerships can help the grandmothers' use their strengths/qualities on the problems?

unstructured question categories: ask each twice (i) about the grandmother herself, then (ii) about the grandmothers in general

state of health/status:
-     physical disability; related to what?
-     diseases - chronic, acute (include over/underweight)
-     perception of health: poor - fair - good - very good - excellent

health practices:
-     substance abuse
-     polypharmacy
-     polydoctoring
-     smoking
-     addictions, including bingo
-     physical, emotional, financial abuse
-     poor disease management
-     less use of traditional practices than desired
-     underuse of ways to prevent disease and promote health eg. stress coping skills, weight control, seeking social support

health services:
-     overprescribed drugs
-     less use of traditional services than desired
-     use of emergency departments, mediclinics
-     lack of understanding of health care system and where and how to go for what
-     need for medical alert system
-     feel used like guinea pigs and given trial drugs, tests
-     limited time given by practitioners for counselling
-     limited or confused understanding of different levels and scopes of responsibility for health services

society in general
-     Are there times when you have felt put down because you're Native?
-     What are some of your feelings when you're talking to someone of authority?
-     Do professionals talk down to you, not with you?
-     Is there a lack of understanding of cultural differences, and the need for cultural transition?
-     Is there a lack of culture-specific opportunities?

issues
-     What do you feel most strongly about? What do you have the greatest desire to do something about?

\-   What other concerns do you have regarding family, finances, getting around, etc.

(Can inquire about emotional times (eg. funerals), drug costs, quality and type of food)

<u>closing</u>:
•   **summarize and reflect back the problems, issues, concerns heard in the responses to which the grandmother most wants to apply herself**
•   thank you

Gerri Dickson   Fall 1994
Project goals, grandmothers' interview guide, consent form

Guide for the Project Evaluation and Participation Interviews
with <u>Grandmothers</u>
in the Grandmothers' Project

The goals of the project are:
1.   to assess the health needs of older Native women in X, and plan and initiate appropriate responses, using a participatory action research approach
2.   to conduct health promotion programming with older Native women in X, from the start of the project
3.   to promote leadership by facilitating opportunities for older Native women to take leadership roles
4.   to strengthen the network of community agencies and programming so as to more adequately and appropriately support the health and well-being of older Native women

The purpose of this interview is 1) to assess the grandmothers' response to participation in the project and the use of participatory action research and 2) to evaluate the project to know if we are meeting our goals - what's going well and what needs to be improved.

1.   When and how did you become involved in the project?
2.   Have you become aware of any changes in yourself or your life since then?
3.   Are there any changes in how you've dealt with these things since you've become involved in the project?
4.   What is different about you? Is there anything different about you since becoming involved in the project?
5.   If this is how you describe yourself now, how do you describe yourself before? How different are you than before?
6.   How do you account for that change? Why do you think that happened?
7.   Can you think what was happening in the project when these things happened?
8.   Have you noticed changes in any of the other participants? how? when?
9.   What are the best things about the project? for you?
10.   Is there anything you don't like? What changes would you like to see?

Consent Form

Date: _____

This is to certify that I, _____, have agreed to participate in the evaluation of the "X Project". The purpose is to 1) assess the grandmothers' responses to participation in the project and the use of participatory action research, and 2) evaluate the project to know what's going well and what needs to be improved.

I understand that:
1. I will be asked questions about the project that have been given to me ahead of time;
2. my responses may be documented in writing and by audiotape and this material will be kept in a locked file cabinet in the project evaluator's home;
3. my responses will remain confidential and anonymous. My name will not appear on the documentation and no individual will be identified in the results of the study, unless I specifically give written permission for this to be done;
4. only the grandmothers, staff, and external evaluator/researcher of the project will have access to my anonymous responses for the purpose of studying and using the information I give;
5. I am free to withdraw from the evaluation at any time and for any reason with no penalty;
6. while some of the results may not benefit me directly, they may benefit others.

Name (print) _____

Name (signature) _____

I do hereby agree to abide by the ethical principles in the conduct of research recognized by the University of Saskatchewan.

_____

Geraldine (Gerri) Dickson, R.N., B.S.N., M.P.H.
The evaluation facilitator and external researcher, Gerri Dickson, may be contacted at the project at 664-5408, the College of Nursing, University of Saskatchewan, Saskatoon, SK   S7N 0W0, phone: 966-6224 or at home at 373-8019

338

Gerri Dickson   Spring, 1996
Project goals, staff interview guide, consent form

Guide for the Project Evaluation and Participation Interviews
with <u>Staff</u>
in the Grandmothers' Project

The goals of the project are:

1.   to assess the health needs of older Native women in X, and plan and
        initiate appropriate responses, using a participatory action research
        approach
2.   to conduct health promotion programming with older Native women
        in X, from the start of the project
3.   to promote leadership by facilitating opportunities for older Native
        women to take leadership roles
4.   to strengthen the network of community agencies and programming
        so as to more adequately and appropriately support the health and
        well-being of older Native women

The purpose of this interview is 1) to assess staff's response to participation
in the project and the use of participatory action research and 2) to evaluate
the project to know if we met our goals.

1.   What was your official role in the project?   in the PAR? What was
        your actual role in each, if there was a difference?
2.   What were your understandings of community development (CD) and
        PAR at the beginning of the project? at the end of the project?
3.   Did you notice changes in any of the grandmothers over the course
        of the proejct? in the PAR? What were they?
4.   Was there evidence that the grandmothers became empowered
        through the project? through the PAR?
5.   What were the best things about the project? about the PAR?
6.   What were the weakest things about the project?   about the PAR?
7.   Have you become aware of any changes in yourself or your life
        because of the project? the PAR? What is different about you?
8.   How do you account for that change? Why do you think that
        happened?
9.   What were the critical events, times, people in the project/PAR
        which facilitated success? which deterred success?

Consent Form

Date: _____

This is to certify that I, _____, have
agreed to participate in the evaluation of the "X Project". The purpose is to 1)
to assess staff's response to participation in the project and the use of
participatory action research and 2) to evaluate the project to know if we met
our goals.

I understand that:
1.   I will be asked questions about the project that have been given to
        me ahead of time;
2.   my responses may be documented in writing and by audiotape and
        this material will be kept in a locked file cabinet in the project
        evaluator's home;
3.   my responses will remain confidential and anonymous. My name
        will not appear on the documentation and no individual will be
        identified in the results of the study, unless I specifically give
        written permission for this to be done;
4.   only the grandmothers, staff, and external evaluator/researcher of
        the project will have access to my anonymous responses for the
        purpose of studying and using the information I give;
5.   I am free to withdraw from the evaluation at any time and for any
        reason with no penalty;
6.   while some of the results may not benefit me directly, they may
        benefit others.

Name (print)   _____

Name (signature)   _____

I do hereby agree to abide by the ethical principles in the conduct of
research recognized by the University of Saskatchewan.

_____

Geraldine (Gerri) Dickson, R.N., B.S.N., M.P.H.
The evaluation facilitator and external researcher, Gerri Dickson, may be
contacted at the College of Nursing, University of Saskatchewan, Saskatoon,
SK S7N 0W0, phone: 966-6224 or at home at 373-8019

From St. Denis V. Community-based participatory research: aspects of the concept relevant for practice.   Native Studies Review 8(2):51-74.

Guidelines   for   Community-Based   Participatory   Research   (CBPR)

A.   CBPR takes time. It should not be seen as an *efficient* way of doing research. For example, time needs to be set aside for everyone in the research process, researchers and community people alike, to get to know each other; and time is needed to allow all opinions, some in conflict with each others, to be heard.

B.   CBPR is more an interpersonal than a technical process because of its emphasis on involving people and eliciting their opinions. CBPR is a human exchange.

C.   For successful CBPR, regularly scheduled research meetings are important because all participants will then know when and how they can give input over the life of the entire research process. The meetings must be well publicized.

D.   A successful CBPR has a lot to do with developing trustworthy relationships between all participants in the process.

E.   In CBPR the process of doing the research is more important that the research product which results because the emphasis is on the relationships between people. The act of doing the research is of primary importance.   That is the essence of community participation.

F.   In CBPR one must be sensitive to the leadership in the community, and that all the *appropriate   people* are properly involved.

G.   Participation cannot be taken for granted. For a variety of reasons, people may be unwilling or unable to participate. For example, community participants may feel they lack the expertise. Others may assume since CBPR is research that it is the *researcher's job.* And finally, many people are just too busy.

H.   The sponsoring or funding agency must be sincere about and committed to the idea of CBPR. However, this commitment creates a dilemma because the agency is likely not to fully understand the implications of CBPR, such as involving potential critics of the agency.

I.   If there are professional researchers with primary responsibilities, they must be aware of their own limitations. For example, a philosophical understanding of CBPR is not enough; some experience in facilitating group discussions and the open flow of information is necessary.

J.   Power and control are central to the process of doing CBPR.   Decision-making must be shared.   For example, professional researchers, if they are involved, must give up their assumed control over the research. Power and control must be constantly negotiated between all participants, but power and control are abstract notions and are often identified only after the fact.

K.   Assumptions cannot be taken for granted.   For example, researchers must examine their assumptions about the community--do they really trust the community?   Is the community capable of interpreting data? For example, community participants must examine their assumptions about what the researcher can or will do.   Does the researcher really know what he is doing?

L.   Professional research language--research "jargon"--should be avoided. This is not a sign of disrespecting the community's intelligence but rather facilitating understanding.

M.   Since the community is probably the participant least familiar with doing research--though they have had research done "on them"--community participants in particular need to know what is expected on them and what they can contribute to the research process.

N.   CBPR is like a community development project.   For example, it takes time, must be responsive to a variety of voices, and must be sensitive to grass-root's opinions.   It is a process of facilitating communication and understanding of the needs of the community.