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Equity Reference Groups: Creating Linkages to Marginalized Communities for Research and Knowledge Translation

This paper reports on the involvement of members of marginalized communities in the Healthy Balance Research Program, which studies the relationship between women's paid work, unpaid caregiving, empowerment and health status in the province of Nova Scotia, Canada. The paper begins with a rationale for the inclusion of marginalized women in research efforts. A brief description of the Nova Scotian context and the partnerships and projects conducted under the auspices of the Healthy Balance Research Program follows. The paper then goes on to describe the development and work of "Equity Reference Groups". These consist of women from four marginalized communities in Nova Scotia: women of African descent; aboriginal women; immigrant women; and women with disabilities. The contributions of these groups are described, and conclusions drawn for future direction of this research program and others like it.

Toward Inclusive Research on Caregiving

Researchers holding a variety of theoretical perspectives and interests have come to recognize that the intersections of gender with other sources of social inequality, such as race, immigrant status, class, sexual orientation or disability, must be taken into account in any agenda of research that takes the advancement of equality and social justice as its *raison d'être* (Canadian Research Institute for the Advancement of Women 1996; Collins 2001; Dill 1987; Hood/Cassaro 2002; Mertens 2003; Olesen 1994). The widespread acceptance of the importance of social determinants of health in improving the health of populations further supports attention to the concerns and perspectives of people whose experiences, needs and interests have not been adequately considered in research and policy efforts to foster good health and well-being (Raphael 2004).

Three organizations lead the Healthy Balance Research Program: the Nova Scotia Advisory Council on the Status of Women, an agency of the Province of Nova Scotia; the Atlantic Centre of Excellence for Women's Health; and the Women's Health Research Unit of the Institute of Population Health at the University of Ottawa. All three share a common commitment to conducting research that "makes a difference" in the lives of women in all their diversity. Their Healthy Balance Research Program takes the work of caring as its topic of investigation, work that is central to the life experience of women:

Care work is women's work. Paid and unpaid, located at home, in voluntary organizations or in the labour force, the overwhelming majority of care is provided by women. It is often invisible, usually accorded little value and only sometimes recognized as skilled. (Armstrong/Armstrong 2001, 2)

Yet from the outset, even at the stage of preparing the proposal for this research program, it was clear that "women" do not form a homogeneous mass of carers. Cultural norms, racism, and discrimination against women with disabilities or against immigrants, limited resources because of geographic isolation or poverty – such factors condition the caregiving experience of women. For that reason, the decision was reached to formulate a research "program" rather than a research "project". In other words, to enable us to reach marginalized communities with culturally sensitive and appropriate research methods and instruments, a multi-method program of research was proposed and eventually funded.

The program was funded primarily through the Canadian Institutes for Health Research under the Community Alliance for Health Research Program, which is intended to foster closer collaboration between university-based researchers and the "community", broadly defined. Additional funding from the Bureau of Women's Health and Gender Analysis of Health Canada enabled us to convene forums of researchers and policy makers on a national basis to share and enrich the work. The Healthy Balance Research Program developed a web of partnerships to provide linkage among the researchers involved, some 20 altogether, and also between the researchers and members of various communities with an interest in using the research results for a variety of purposes. These would include the formulation of evidence-based advice to inform policy and program initiatives and development of information and education materials for caregivers, for example.

An integral part of the research program's structure are four groups of women from four marginalized groups in Nova Scotia: First Nations women; women of African descent; immigrant women; and women with disabilities. Known as the Equity Reference Groups, these women have contributed in a variety of ways throughout the research process, from project initiation onward, now beginning to address the ways in which the research results can be used in their communities. Before discussing these groups in detail, a brief overview of the Healthy Balance Research Program is presented.

Components of the Healthy Balance Research Program

As indicated above, the objective of the Healthy Balance Research Program is to deepen our understanding of unpaid caregiving and its effect on women's lives, with a particular focus on their health status. Women care for others throughout their adult lives: for children and for adults, particularly in case of illness, disability or frailty associated with age. Given the enormous rise in participation in the paid workforce by women over the past generation, it may be expected that there would be associated effects on total workload, including paid work and unpaid work in the home. At what point does the nature and sheer volume of such work, especially caregiving, become problematic? When and how does it affect women's health? What policy and program measures are helpful now, and what needs to be done to further develop supportive measures? How do these issues play themselves out in aboriginal and African-Nova Scotian contexts? For women with disabilities? For immigrant women? These are the questions that initiated our inquiry.

More formally, the research questions to be addressed are as follows:

- What is the prevalence of different kinds of unpaid caregiving in Nova Scotia? How are different kinds of caregiving shared between women and men?
- What unpaid caregiving situations, on their own or combined with paid work, are associated with positive or negative health status? How does empowerment act as an intervening variable?
- How do social determinants of health interact with paid work, caregiving, unpaid work and health status? Race, culture and ethnicity; rural and urban location; income; age of the caregiver; type of occupation and employment status; family composition and status; formal and informal assistance and support were of concern.
- How helpful are current policies and programs that address paid work and family life? How could they be improved?

Four research teams were developed to address these questions, and two specific papers were commissioned (Armstrong and Armstrong 2001; Shillington 2004). Two research teams had a qualitative focus: the first conducted focus groups with particular attention to caregivers who were aboriginal, African-Nova Scotian, immigrants and women with disabilities. The second of the two qualitative research teams conducted a series of fourteen in-depth ethnographic studies of caregivers, again including women of diverse backgrounds. Two additional research teams focus on quantitative data: the first of these was charged with the analysis of secondary data sources relevant to the questions. The second team developed a survey of Nova Scotia's population to determine the prevalence, nature and scope of caregiving. At this time, the winter of 2006, data collection is complete and a number of reports from the research are available.¹

Findings reported to date from the focus groups identify the degree to which the caregiving role is central to the identity of many women, with particular emphasis in African-Nova Scotian, First Nations, and immigrant communities, but equally present in others. The influence of cultural differences, complex family dynamics, difficulties in access to transportation and various kinds of supportive services, as well as consequent health impacts on caregivers are discussed by Gahagan et al. (2004). Additionally, the experience and perspectives of caregivers from the four equity groups is discussed, showing the impact of cultural norms, deficits in access to information about services, and the additional difficulties imposed by disability in the caregiver. Caregivers did make use of a wide variety of community supports and home care, generally speaking well of these services. At the same time, utilization and coordination of services can itself be a source of stress. Gahagan et al. (2004, 37) write "caregivers often walked an interpersonal tightrope of diplomacy held together with a healthy measure of humility in order to secure resources [...]."

The ethnographic case studies of 14 caregivers and their families involved intensive observation and interviews by trained research assistants. Of the participants, four were of European descent, two rural and two urban. Two women had disabilities. Two women were of African descent, one living in the city and one in the country. Two women were selected because they are lesbian, and one additional caregiver subsequently identified herself as lesbian as well. Of the two First Nations women, one lived on a reservation and one did not. Two women were immigrants. Beagan (2005) provides a rich description of the caregiving relationships in these fourteen families, identifying the tensions accompanying these roles and the difficulties arising from interaction with helping agencies. Such difficulties often arise from mistaken, unspoken assumptions about caregiving that underlie policy and program development. Some examples of the latter include what Stadnyk and Beagan (2005) have called "familism" and "residualism". Familism concerns the assumption that it is "natural" for families, and more specifically women in families, to provide care. Residualism refers to the assumption that publicly funded supports for caregiving should only be available after a family has exhausted all its own resources. Both sets of assumptions should be questioned and alternative scenarios developed.

The secondary data analysis team used General Social Survey (GSS) data collected by Statistics Canada from February 1998 through January 1999 to examine the impact of paid and unpaid work on women and men aged 25-

¹ See the Healthy Balance Research Program web site www.healthyb.ca.

54. The survey is representative of Canadians, and includes 3304 women and 2947 men. Although sample sizes for Nova Scotia were not sufficient to allow estimates at the provincial level, Phipps, MacDonald and Lethbridge (2005a) were able to use the data to provide a national perspective on the impact of the total hours of work on stress in women and men in relation to the presence of children, elders or both in the home. Total hours of work included paid work, housework, care for children and care for elders. For women, stress increased with the number of paid work hours, but not with childcare. However, stress for women was greatly increased through eldercare. Housework, on the other hand, raised the stress levels of men, but childcare and eldercare did not. These findings are of interest in light of survey findings that for many women paid employment is rewarding, and can mitigate stressors that exist when only unpaid work is performed in the home. It would appear that the “double work load” of paid and unpaid work is particularly stressful for women when paid work, childcare and eldercare demands occur simultaneously. Phipps, MacDonald and Lethbridge (2005b) were able to analyze these data at an Atlantic Canada level, including the four eastern provinces, Nova Scotia, New Brunswick, Newfoundland, and Labrador and Prince Edward Island. In comparison to Canada as a whole, Atlantic Canadian women spend significantly more time in caregiving activities, although the reasons for this are not known. What was determined by the study is that none of the demographic and socio-economic variables available in the survey served to explain this difference between women in Atlantic Canada and the rest of the country.

The fourth project in the Healthy Balance Research Program consists of a survey of Nova Scotians. Telephone interviews were conducted with 1988 screening interviews and 465 in-depth interviews with caregivers. The 1988 screening interviews constitute a representative sample of the adult population of Nova Scotia, and will allow a description of the prevalence of caregiving in that population. The in-depth interviews include both women and men in rural and urban areas of the province and will be the focus of monographs discussing the relationship between caregiving and paid employment; and the impact of caregiving on a variety of health behaviours and issues.

Having given an overview of the research activities, this paper now returns to a consideration of the role of the Equity Reference Groups in the research process itself, and its planned role in the future utilization of research results.

The Role of Equity Reference Groups

Health researchers – and their funders – show increasing interest in the utilization of their research. In Canada, the Canadian Health Services Research Foundation invests considerable resources in the development of initiatives to foster the uptake of research findings and implications into professional practice and health policy. The Canadian Institutes of Health Research also maintain a serious commitment to research that is useful in improving the health of Canadians, by fostering the process of knowledge translation, defined as follows:

Knowledge translation is the exchange, synthesis and ethically sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.
(Canadian Institutes of Health Research)

In the United Kingdom, the participation of consumers in health and social research has become a requirement of some types of funding, and in consequence, extensive guidelines and resources for facilitating such involvement have been developed (INVOLVE; Folk.us).

The “complex system of interactions” among researchers and users, as exemplified in the Equity Reference Groups that are an integral part of the structure of the Healthy Balance Research Program, will be the focus of the rest of this paper. First, a brief discussion of the population context is presented – what is Nova Scotia’s population, and how do First Nations, African-Nova Scotian, and immigrant people compare? What is the prevalence of disability in the province?

Nova Scotia: Population Characteristics

Nova Scotia is one of Canada’s smaller provinces, with a population of about 938,000. Along with other provinces in Atlantic Canada, Nova Scotia has for generations had substantial out-migration, with people leaving to seek employment in Central and Western Canada.

Halifax is the largest centre, with a population of 380,000, followed by Cape Breton Regional Municipality at 106,000. About half the population, then, lives in small towns, villages and rural areas of the province, and there are important differences in socio-economic characteristics of the population in urban and rural areas. The relatively high proportion of rural population requires appropriate modifications of health and social service delivery to address the realities of rural life.

Nova Scotia has an aging population, with 12.3% of men and 15.8% of women aged over 65. Among persons aged 85 years and older, 71% are women. Fertility rates have undergone a long-term decline, from 4.1 at the height of the baby boom in 1961, to approximately 1.48 in 2003. The province of Nova Scotia also has a higher proportion of

persons with disabilities than Canada as a whole: 20.1% of Nova Scotians reported a disability compared to 14.6% at the national level (Nova Scotia Department of Finance Economics and Statistics Division 2005).

The original inhabitants of Nova Scotia are Mi'kmaq people, whose history is eloquently portrayed by Paul (2000). Now, there are 13 Mi'kmaq First Nations communities in Nova Scotia (Office of Aboriginal Affairs 2006). Census data from 2001 indicate that there are approximately 30,000 aboriginal persons in Nova Scotia (Statistics Canada 2001a). Mi'kmaq people face serious jurisdictional issues arising from the Indian Act, which provides a range of benefits and services, including education, health and housing to "on-reserve" residents, but not to those living "off-reserve". The health status of the Mi'kmaq was surveyed by the Mi'kmaq Health Research Group (1999), which continues to work with the Atlantic Aboriginal Health Research Program. Overall, health indicators for Mi'kmaq communities demonstrate higher rates of health problems than the population as a whole, and as a result there are more demands for and on caregivers in those communities.

People of African descent came to Nova Scotia during its earliest settlement period. With the defeat of the British in the American Revolution, the first larger wave of African-Nova Scotians arrived in Canada, along with the British refugees leaving the new American republic. The history of African-Nova Scotians is documented by the Black Cultural Centre for Nova Scotia. Census data from 2001 indicate that there were 19,670 African-Nova Scotians and the provincial government Office of African Nova Scotian Affairs presents data on their current situation, which reflects continuing social exclusion and disadvantage. African Nova Scotian community life is traditionally centred on the church, but the Office of African Nova Scotian Affairs notes "community cohesion is not as strong as it has been in the past". This factor would particularly affect caregivers who may not have the informal community supports that they would have had at one time.

Canada is a "nation of immigrants", but Nova Scotia has not been their destination as frequently as the major urban centres of Toronto, Montreal and Vancouver. Nova Scotia's population has 41,315 persons who are foreign-born, 4.6% of the total population. Just over 10,000 of these immigrants arrived after 1991, with about 70% settling in Halifax (Statistics Canada 2001b). In order to increase the number of immigrants choosing Nova Scotia as their new home, the provincial government is implementing a new immigration strategy, with the intention of increasing immigrant settlement in the province. Immigrant caregivers face difficulties in finding their way through the complex of services that might be of assistance to them, and may face additional difficulty in getting culturally appropriate health services.

Disability was the fourth source of inequality that the Healthy Balance Research Program decided to take into account in its research projects. Statistics Canada's (2001c) Physical Activity Limitation Survey shows that Nova Scotia has the highest rate of disability in its population of any of the Canadian provinces, at 20.1%. The survey defines persons with disabilities as those "who reported difficulties with daily living activities, or who indicated that a physical, mental condition or health problem reduced the kind or amount of activities they could do." Persons with disabilities are often stereotypically construed as care receivers rather than as care givers, and therefore the decision to include the voices of women with disabilities in the research program was considered to be of great importance. As daughters, as partners, as mothers, women with disabilities carry out the work of caregiving with heightened challenges, about which little was known and for which policy and program initiatives taking various forms of accessibility into account would be of particular importance.

Recruitment of Equity Reference Group members

Both the Nova Scotia Advisory Council on the Status of Women and the Atlantic Centre of Excellence for Women's Health had good liaisons with women in the four equity reference groups before this research program was initiated.

The Advisory Council on the Status of Women is a provincial government agency with the mandate of advising government and bringing forward the concerns of women. The Council itself consists of approximately 12 women appointed by the Minister responsible for the Status of Women, and is supported by a staff of 10, of whom 3 are part-time. The Council members include members from each of the Equity Reference Groups, who were of great assistance in recruiting additional members. In fact, three of the current Advisory Council members, one past member, and one staff member have participated in the work of the Equity Reference Groups from the beginning.

The Atlantic Centre of Excellence for Women's Health also had strong contacts, particularly in the health sector, with women from the Equity Reference Groups. Recruitment then, proceeded by "word of mouth", and the program had no difficulty in attracting women to these groups, including women from rural areas of the province. It should be noted that participants are compensated for their travel and caregiver replacement costs, but are otherwise unpaid, although some have employers who fund their participation.

Altogether, there were approximately 20 reference group members recruited, 5 from each equity group. Over the 5-year life of the project, there were some departures over time, but overall the original group stayed with the program. The women bring with them not only their personal experiences, but also extensive community networks. Although the Equity Reference Group members participate as individuals rather than as representatives of agencies or organizations with which they might be affiliated, most of them are involved in a wide variety of community and/or employment contexts. All are active citizens with an interest in promoting positive social change.

The Roles and Involvement of Equity Reference Groups

At project initiation, the Equity Reference Groups met separately, to discuss with the researchers how their work could be inclusive of their life experience and circumstances. Issues discussed at length included the meaning of caregiving in various communities, the challenges associated with it, what similarities and differences were thought to exist. Interestingly, there was disagreement at the outset over what caregiving entailed. For example, some consider that childcare is a part of caregiving, while others preferred to reserve that term for either children or adults who required care because of disability in the case of children, or disability, age or frailty on the part of adults. What became clear in the dialogues is that caregiving has varied meanings, and the definitions used in much of the caregiving literature did not resonate with everyone.

Another important discussion dealt with the question of how to recruit study participants from each of the communities and how focus groups and interviews could be structured in a culturally appropriate and respectful manner. The contributions of the Equity Reference Groups to these discussions were enormously helpful to the researchers, and the Equity Reference Group members acknowledged their enjoyment of the egalitarian dialog with the researchers – in many ways, the work became a joint exploration.

After the first meetings of the Equity Reference Groups, where they met separately, subsequent meetings were held jointly, at the request of the group members. The individual groups all agreed that they preferred to share their experiences and views with the larger group and felt no need to meet separately.

During the first two years of the program, during its formative stages, the Equity Reference Groups met about 3 times a year. These meetings were held over two days, and were carefully structured and facilitated to ensure that everyone was heard and that the questions addressed were important to both researchers and Equity Reference Group members. In the first years, comments on the research process, data collection instruments and interpretation, particularly of focus group results, were substantial contributions.

When the ethnographic research team was ready to begin its data collection, Equity Reference Group members were given the opportunity to participate as research assistants. Three of the women took up the offer and received extensive training in order to carry out the work of interviewing and participant observation, with very positive results in terms of high quality information-gathering and insightful observations.

Once data collection was underway, the frequency of meetings declined, since there were no results to review yet. At this time, from winter 2006 through the end of the program in March 2007, there will be at least 3 meetings of the Equity Reference Groups to review the research results and address the important “knowledge translation” question of what kind of information should be made available, and how it should be brought back to their communities.

Initial discussions about community feedback mechanisms had already been held in general terms. For example, at the meeting of February 2003, when early focus group results were reported to the Equity Reference Groups, they identified the need for developing separate presentations on each of the equity groups, suggested a wide variety of service providers who should be contacted, that health organizations throughout the province should be informed, that employer and labour groups were important audiences for this research and that church groups also would benefit from hearing about the research results.

What is interesting is that the Equity Reference Groups see a much wider audience of potential users of the research information than that originally envisaged. In particular, they have much less interest in the academic publications the program generates than they do in policy and program-relevant materials to influence decision-makers, and in practical “how-to” materials to assist caregivers. They recognize that a policy and program environment that addresses the support needs and health issues of caregivers must move beyond the boundaries of the health care system and go into the communities, where a wide range of leaders and policy makers can be reached with recommendations on how they are needed to build a society where care is not a “problem”, but is recognized as an important purpose of society (Armstrong/Armstrong 2001).

Concluding Discussion

The involvement and generous contribution of time and knowledge by the Equity Reference Groups has produced a situation in which research results can be “translated” into materials that are meaningful to the population that took part in the research. For example, a “Guide for Caregivers” will be produced, addressing the many concerns that were raised by the research participants. That Guide will be able to address issues in a culturally appropriate and inclusive manner, thanks to the contributions of the Equity Reference Groups, which deepen the understanding of what information would actually be useful to a caregiver.

In order to reach policy audiences and program staff, as well as members of the business community, plans are being made to hold a Healthy Balance Forum in May, 2006.

A communications plan is being developed in order to bring the needs of caregivers to wide public attention through media aimed both at professional audiences, such as Home Care staff, and at the general public, with the aim of building a climate of support for caregivers.

All these projects point to a challenge arising from the involvement of Equity Reference Groups, or more generally, from a commitment to research that “makes a difference”, that is seriously committed to using the research information for the benefit of those who participated in it. The principal challenge is time. It is far more labour-intensive for the researcher to work on a continuing basis with a user group than it is to do traditional positivistic research, alone in the office with the computer. Unfortunately, current practices of evaluating the contributions of researchers are excessively focussed on the production of papers for the academic press, and work with communities or, for that matter, government agencies, and that does not translate into a publications record receives little or no acknowledgement. Especially for the younger researcher facing high teaching loads and enormous pressure to publish, participating in work that has a strong community component can be extremely difficult.

One way to address that difficulty is to work closely with agencies (such as the Nova Scotia Advisory Council on the Status of Women) that have a strong community outreach component in place, and that can assist with the time-consuming minutiae of meeting organization, preparation of user-friendly documents and materials, linkage to a variety of government bodies and provision of media services. Community participation requires the development and maintenance of committed partners and the experience of the Healthy Balance Research Program will be widely shared as an example of community involvement and outreach for research and knowledge translation (Amaratunga, Neumann and Clow, 2006). The ongoing partnership with the Women’s Health Research Unit at the University of Ottawa is one way of extending methods for conducting inclusive research and knowledge translation beyond our provincial borders.

Overall, the participation of the women in our Equity Reference Groups has been a mutually enriching experience. There are no participants, either researchers or group members, who have not gained a deepened understanding of the meaning of caregiving in the lives of women of diverse backgrounds. We are all sometimes overwhelmed with the sheer complexity of the lives that face many caregivers, and at the same time are reinforced in our commitment toward a society that treats this vital, unpaid, and too often unacknowledged contribution of women more equitably.

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