

A Healthier Balance of Expertise: An Innovative Model for Community-University Alliances in Health Research

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Abstract

As a research model, the Healthy Balance Research Program stands as a successful alliance between researchers, community organizations and policymakers. Its advisory bodies (equity-seeking populations and policymakers) provide checks and balances to traditional academic research structures, and overall help ensure information uptake and community engagement with unpaid caregivers in Nova Scotia.

Résumé

En tant que modèle de recherche le Healthy Balance Research Program est vu comme une alliance avec succès entre les chercheurs, les organismes communautaires, et les décideurs. Ses comités consultatifs (population et les décideurs qui recherchent l'équité) offre les contrôles des structures de recherches académiques traditionnelles, et en général aide à assurer la distribution de l'information et l'engagement de la collectivité avec les personnes qui ne sont pas payées pour donner des soins à un proche en Nouvelle-Écosse.

Introduction

The Healthy Balance Research Program (HBRP) is a multi-method, multi-year project - funded by the Canadian Institutes for Health Research (CIHR) - that has the goal of understanding the relationship between women's health and well-being, unpaid caregiving and earning a livelihood. It is founded on a partnership between three main organizations: the Atlantic Centre of Excellence for Women's Health at Dalhousie University, the Nova Scotia Advisory Council on the Status of Women, and the Institute of Population Health at the University of Ottawa. Four teams of university-based researchers, a policy advisory group, and four groups of women from equity-seeking populations in Nova Scotia round out the research team.

The HBRP is an innovative project - in design, in methodology and in many of its conclusions. For example, some researchers involved in the project conducted the first population-based survey of caregiving in Canada while others developed costing analyses of caregiving and the burden of caregiving for women. One of the most interesting innovations of the project relates to the research process, specifically the model of community engagement. From its inception, HBRP has worked to include the voices of women from equity-seeking populations as well as the perspectives of decision makers inside and outside of government. Engagement with community and policy partners has served to build capacity - within government and communities as well as among researchers

- and to create strong, broad, and stable networks for the exchange and translation of knowledge. As a result, researchers have become more aware of and more responsive to the needs of community caregivers while the findings of the research have been translated more easily and rapidly to community and policy audiences. As we suggest here, the model for community-university collaboration developed for the Healthy Balance Research Project appears to be a promising new practice for health researchers working with and for communities.

Background

In 2001, the Healthy Balance Research Program became one of the first Community Alliance for Health Research (CAHR) projects funded by the then newly-established Canadian Institutes of Health Research. Like the Community-University Research Alliance (CURA) program of the Social Sciences and Humanities Research Council of Canada, the CAHR program had at its core the goal of promoting "mutual learning and collaboration among community organizations and researchers about health and health care issues of concern to the community" (CIHR 2000; 2006). No specific model for collaboration between university-based researchers and community partners was defined by CIHR, but every project was expected to ensure "that groups from the community be active and ongoing participants in research, training and dissemination activities, and that their roles have been agreed upon in a spirit of equity and mutual benefit" (CIHR 2000). The original 19 CAHR projects funded by CIHR adopted different approaches for ensuring community engagement, ranging from formal agreements between organizations to membership on advisory or management boards to informal integration of community partners into research teams (CIHR 2006).

Like other CAHR projects, the Healthy Balance Research Program built on

existing relationships with community and policy partners, but HBRP also stands out from many other CAHR projects in that the research subject and methods were conceived jointly, by university-based researchers, policy partners and community-based organizations (Birdsell *et al.* 2002). Indeed, the Nova Scotia Advisory Council on the Status of Women, a provincial government agency, initiated discussions about the relationship between women's health and unpaid caregiving and worked closely with the Atlantic Centre of Excellence for Women's Health, a non-profit research agency affiliated with Dalhousie University, to formulate the project funding proposal, to engage with researchers and community partners, and to manage the five-year project. At the same time, HBRP actively sought to engage women from historically disadvantaged and under-represented groups to ensure that the research questions, tools and processes were inclusive, comprehensive, and culturally appropriate. Four groups, called Equity Reference Groups or ERGs, were formed to engage African Nova Scotian, First Nations, immigrant women and women with disabilities in the research. Community and policy partners were also invited to sit on a policy advisory committee (PAC) with a view to ensuring that policy recommendations from the project were properly framed and disseminated to a variety of audiences.

In their original incarnation, the ERGs had an important advisory role in the project, meeting two to four times a year to provide input on the cultural appropriateness of the research, to get updates on the status of the research and research findings, and to advise on and assist with knowledge translation. But the ERG members recognized that they had a great deal more to contribute to HBRP and began to get involved in the research in various, sometimes unexpected, ways. The PAC did not figure in the initial funding proposal, but evolved out of a growing realization that the project needed additional

community and policy engagement to ensure that policy recommendations based on the research findings would meet the needs of caregivers throughout Nova Scotia. Committee members, many of whom were strategically located in government and community-based organizations, also served as key partners in knowledge exchange. At the close of the project, an independent evaluator conducted focus groups with the ERG and PAC members to assess the strengths and limitations of the HBRP approach to community engagement. Drawing on these evaluations and other project documents, we begin to see the challenges of community engagement as well as the potential of the HBRP approach to health research.

An Inclusive Community-University Partnership

A burgeoning literature in recent years has documented the health inequities experienced by those in diverse and vulnerable population (Raphael 2004). People of colour, people living in poverty, people with disabilities or newly arrived in Canada - as well as women in every group - face greater risk of illness and other types of disadvantage. The situation is no different in Nova Scotia. Although we have the smallest proportion of immigrants in the country, we also have the largest population of indigenous African Canadians - those living in Canada for many generations. We also have some of the highest rates of illness and, as a "have-not" province, among the highest rates of low income in all of Canada. These realities led the designers of the Healthy Balance Research Program to place priority on the experiences of marginalized communities of women. In addition to planning focus groups and other data collection methods with women from diverse populations, the project design included a proposal for four equity reference groups, comprised of women from First Nations, African Nova Scotian and immigrant communities and women living with disabilities. This is not to suggest that

other women have not experienced vulnerability, marginalization or disadvantage, but rather that these four populations have developed a degree of social cohesion, identity and activism in Nova Scotia that provided an opportunity for enhanced engagement. Building on existing partnerships and networks, the Directors of HBRP contacted individuals and organizations positioned to represent the needs and perspectives of the four equity-seeking populations. Although there has been some turn-over in the ERGs during the life of the project, by and large the membership has been remarkably stable, with a total of 16 women from the African Nova Scotian, immigrant and Mi'kmaq communities and women with disabilities working on the project.

Each of the ERGs brought specific strengths and experiences to HBRP. A majority of women of African descent living in Nova Scotia come from families and communities established in the region during or in the aftermath of the American Revolution. Centuries of oppression and discrimination have laid the foundation for many types of disadvantage while persistent racism and exclusion have served to intensify health inequities. At the same time, the history of African Nova Scotian communities - including current experiences of systemic discrimination - have fostered resilience and the centrality of family and community. Women in these communities take on a great deal of responsibility, caring for those who are ill or require assistance.

First Nations women in Nova Scotia have likewise experienced historic and persistent discrimination, with similar effects on their health and well-being. Mi'kmaq women in Nova Scotia, whether they live on or off reserve, are far more likely to be living in poverty and with a variety of illnesses than are their non-Aboriginal counterparts. Like African Nova Scotian women, Mi'kmaq women are also highly resilient and undertake much of the work involved in caring for children, elders and those who are sick. Their intimate knowledge of

Mi'kmaq language and culture, as well as the issues facing First Nations communities, has contributed to the development of culturally appropriate research questions and methods (N. MacDonald *et al.* 2005).

As mentioned earlier, Nova Scotia and the Atlantic region as a whole receive the smallest proportion of newcomers to Canada. But as the labour force continues to shrink, governments are increasingly interested in learning why immigrants go elsewhere, either initially or after living in Atlantic Canada for a few years. Limited employment opportunities contribute to the small numbers and transience of immigrants in Nova Scotia, but immigrant women have identified other challenges affecting their experience of life in Canada, including social, linguistic and cultural isolation and systemic discrimination. These challenges, like those facing Mi'kmaq and African Nova Scotian women, contribute to and exacerbate health disparities. Like Mi'kmaq and African Nova Scotian women, immigrant women also shoulder the responsibility of providing care to family and to others in their social networks, often without access to services and other supports.

Women with disabilities living in Nova Scotia face many barriers to health and care. They are more likely to live in poverty and experience various forms of isolation, which limits access to services and supports. If they have sight, hearing or mobility disabilities, they are further challenged by the structured environment and by policies as diverse as snow clearing by-laws and the development of public transportation. Moreover, women with disabilities are often rendered invisible when people assume that they can only be recipients of care. Women with disabilities speak of facing overwhelming barriers to access services, including exclusion from policy, programs and services that fail to recognize their roles as mothers, sisters, friends, caregivers and community members (Neumann 2006).

In comparison to the Equity

Reference Groups, which were embedded in HBRP from its inception, the Policy Advisory Committee was established later in the project. As research evidence accumulated and themes emerged from the analysis, it became important to convene a group of experts, from inside and outside of government, who could lead the development of key policy recommendations and knowledge translation strategies with the greatest potential for policy uptake. Building on relationships that had existed prior to HBRP as well as those established and strengthened through the project, the PAC brought together members from the ERGs and a broad range of community, non-profit, private and public sector representatives. Working together, the members of the PAC helped to synthesize the research and provided critical insight into the policy implications of the project. PAC members also offered important advice about media, formats, language and methods of dissemination.

Community Engagement in Action

While the original mandate of the ERGs was to ensure cultural appropriateness of the research and facilitate dissemination of findings within communities, the members of the ERGs saw and developed many opportunities for additional input into the project. ERG members collaborated with university-based researchers, both quantitative and qualitative, to refine the research questions and tools. The population-based survey, for instance, went through many iterations as the research leader for this portion of the project sought the advice of ERG members and amended the survey instrument accordingly (Keefe *et al.* 2006). In the case of the focus groups, members from the Women with Disabilities group questioned the emphasis on research participants who had mobility challenges, encouraging the researchers to involve women living with other types of disabilities. All the ERG members contributed to the development of

recruitment strategies and, in some cases, they became a primary avenue for recruitment. As a result, more and more diverse women participated in the project than might have done so without the liaison work undertaken by the ERGs (Crewe 2007). ERG members also facilitated focus groups and some were trained as research assistants. The ethnographic research, in particular, benefitted from the involvement of ERG members as research assistants. Having been trained in research theory and methods, these ERG members worked closely with caregivers in their homes to create powerful, diverse and intimate portraits of caregiving in Nova Scotia (Beagan *et al.* 2006). These stories, in combination with other qualitative and quantitative findings, have helped to create a compelling case for policies, programs and other resources that will support unpaid caregivers. ERG members have also been instrumental in the design of resources, including a Caregiver's Handbook.¹ To date, more than 11,000 copies of this guide have been distributed to practitioners, researchers, community organizations, regional health planning agencies, and health care facilities throughout Nova Scotia.

The Policy Advisory Committee, which also included ERG members, contributed to HBRP in its final stages by assisting with knowledge synthesis and translation. Although most were not involved in the collection of data, the PAC members influenced the analysis of data and the ways in which the research findings were being packaged for diverse audiences. They not only crafted the policy recommendations for the project, based on the research findings, but also initiated the development of a Community Action Kit¹ that would provide Nova Scotians with resources needed to present a consistent evidence-based message to local MPs and MLAs about improving the health and well-being of unpaid caregivers in every constituency in Nova Scotia. PAC further developed a series of key policy recommendations from

the project and these have been and continue to be presented to relevant departments within the Nova Scotia government as well as to communities across the province.

During the life of the project, the discourse on and response to unpaid caregiving in Nova Scotia has shifted dramatically. In the 1990s, various government consultations and strategies acknowledged the crucial service provided by unpaid caregivers, but beyond slight improvements in specific programs, such as respite care, little was done to support unpaid caregivers (Clow 2001; Campbell *et al.* 1998). Moreover, while noting that unpaid caregivers are usually women, government initiatives ignored the gender dimensions of this work. Unfortunately, gender-blindness continues to characterize the new Continuing Care Strategy for Nova Scotia, released in 2006, but the importance of supporting unpaid caregivers is acknowledged and addressed in the document: "Caregivers are partners in care and clients in their own right. A comprehensive caregiver strategy will include caregiver assessment and a menu of supports that offer choice and meet social, economic and health needs" (NS Dept of Health 2006). While HBRP cannot and would not claim to have alone changed the discourse on caregiving, the engagement of community partners armed with compelling evidence about the realities facing caregivers has contributed to a growing realization - in government and elsewhere - that unpaid caregivers are crucial to the health and fabric of Nova Scotian society. The Strategy opens with the following observation: "Neighbours helping neighbours, parents encouraging their children, adults caring for their aged parents, and individuals supporting their communities through volunteering - these attributes are what make our communities strong,...[and] also set a strong foundation for government programs and services aimed at helping Nova Scotians achieve maximum health and independence" (NS

Dept of Health 2006).

The Benefits and Challenges of Community Engagement

Among the most obvious benefits to HBRP of community engagement has been heightened awareness of the needs of diverse groups of women providing unpaid care in Nova Scotia. ERGs have been "useful critics, pointing out the weaknesses in secondary data that do not reflect the realities of caregivers of various cultural backgrounds and ability status" (Amaratunga *et al.* 2006). At the same time, community engagement has contributed to capacity building across the team and in communities. University-researchers involved in HBRP have gained new insights about how best to adjust research instruments and methods to capture the experiences of diverse and marginalized populations. Many have also come to appreciate the limitations of specific research methods: population-based surveys, for example, cannot represent the realities facing diverse communities in jurisdictions, such as Nova Scotia, where small numbers may threaten confidentiality. Communities have also gained new knowledge and/or evidence confirming their experiences and needs. In some cases, communities have acquired new research resources in the form of facilitators and research assistants trained during the project. Ultimately, the research capacity of Atlantic Canada has been enhanced substantially by the networks and partnerships forged and extended during the research program, setting the stage for future research partnerships among marginalized communities, private and public sector representatives, policy makers and academic researchers.

While community partners were generally satisfied with their involvement in the project, community engagement in HBRP was not without challenges. Evaluations of both the ERGs and the PAC in the final stages of the project provided an opportunity for members to discuss what

worked well for them and what did not. The ERG members were consistently positive about the program and its accomplishments, but they clearly also wished for more direct, substantial, and sustained participation in all facets of the research. Specifically they commented on interruptions in communication that left them unsure about the status of the work, about limited opportunities to contribute to recruitment strategies, and about the extent to which they did not see themselves reflected in the quantitative research evidence generated by the project. PAC members similarly reported positive experiences with the project, describing how the committee experience allowed them to gain a deeper understanding of the issues facing caregivers and to develop sustainable inter-sectoral networks and partnerships. As one member said, "Interaction within the group was one of the best things about the PAC - together we were better, I think, than the individual parts." But like the ERG members, some PAC members wanted more opportunities and more involvement. Several mentioned that both they and HBRP would have benefitted more had the committee been struck earlier in the project. The PAC evaluation also revealed a degree of unevenness in attendance and participation among committee members.

Interestingly, many of the concerns raised by community partners in HBRP appear to crop up regularly in research founded on community-university alliances. Differing cultures, needs and expectations among the partners can contribute to misunderstandings or under-utilization of skills. In an early evaluation of the CAHR projects conducted for CIHR, for instance, the authors noted that distance among partners tended to increase the challenges associated with "keeping community partners involved and active," particularly when project designers had not budgeted enough resources for face-to-face interaction and on-going communications (Birdsell *et al.* 2002). This was certainly the case for HBRP; community partners from

across the province met two to four times annually, but these meetings did not always dovetail with significant points in the research cycle and communication between meetings was sometimes neglected, particularly early in the project.

Similarly, Birdsell and colleagues reported that varying time frames, organizational expectations and career imperatives could trouble partnerships. "In the conventional academic cycle," they wrote, "research has a long-term horizon. Community partners, in contrast, are working on a short-term frame. They need fast results that can be applied quickly and strategically" (Birdsell *et al.* 2002). These kinds of tensions were evident in HBRP with respect to knowledge translation; co-directors and program staff were regularly confronted with the task of balancing the needs of community partners for readily accessible information with the needs of university-based researchers for embargoed peer-reviewed publications. Together, the project team developed an approach that seemed to meet the needs of both groups, developing plain-language documents for general distribution while supporting academics to write scholarly articles.

Differing views of intellectual property and authorship as well as differing expectations of community and university partners were identified by Birdsell and colleagues as other potential sources of problems. Some university-based researchers and many funding agencies believe that the research needs to be controlled by academics. But community partners, like some academic researchers, tend to believe that universities provide leadership rather than control of the research. Differing expectations certainly appeared in the ERG evaluation of HBRP.

Community partners had anticipated greater involvement in setting the research agenda, formulating research questions and influencing the research instruments and processes, but some of the university researchers operated on a more

individualistic or academic model of research. The ERG evaluators concluded that "better facilitation is necessary between community-based and academic sectors, as is an appreciation of what motivates and drives each of them and where these motivators and drivers intersect" (Hollett 2007) .

Despite the many potential pitfalls associated with community-university research alliances, it is evident that the benefits and opportunities have outweighed the challenges for those involved in HBRP. ERG members told the evaluators that they felt the model was "a success and that this inclusive application is long overdue in community-based and academic sectors" (Hollett 2007). One PAC member, clearly familiar with the ERG model, suggested that it could be utilized to good effect elsewhere. Other PAC members noted that the committee had respected the knowledge and contributions of everyone in a highly collaborative process. With some refinements, particularly clarifying roles and expectations for all the partners and ensuring sustained engagement throughout the research, it appears that the model of community-university partnership developed through the Healthy Balance Research Project has promise as an innovative approach to health research. Community engagement is especially important when conducting research related to marginalized and disadvantaged populations, and research with the most vulnerable of these populations - women.

Conclusion

Increasingly, research funding agencies in Canada and elsewhere in the world are emphasizing the need for applied research, research that can make a difference for populations and communities. Broad-based community partnerships are key to this kind of research because knowledge of local needs and local realities is essential to the formulation of meaningful research questions and culturally appropriate research processes. In this

sense, HBRP has made an important contribution to the evolution of thinking about unpaid caregiving in Nova Scotia. In 2006, the authors of the Continuing Care Strategy for Nova Scotia observed that, "Nova Scotians have told us that they want [existing] services and more, and they are ready for change" (NS Dept of Health 2006). HBRP, founded on a vibrant alliance of community, government and academic partners, has helped to generate the evidence underpinning this message and helped to translate this message from community to government. While the HBRP model of community engagement is not perfect, as we have seen, it shows considerable promise as a mechanism for ensuring that the best questions are asked, the best methods are employed, and that people who can foster change learn about the research at the most opportune times.

Endnote

1. For further information and copies of these documents, see www.healthyb.dal.ca

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