

Original Research Design (as proposed in October 2001)

The research component of this project draws upon a participatory action research framework of 'health promotion for social change', in which Hispanic women are supported to analyse their own situation, so that they can decide what is best for their own health; rather than a 'banking' approach to health education (in which Hispanic women would be seen as an empty vessel into which a health educator will pour appropriate knowledge). Hispanic women in the community will be empowered to actively make changes in their situation - consistent with the WHO concept of health promotion as 'the process of enabling people to increase control over, and to improve, their health'. Participatory research emphasizes valuing people's knowledge of their own situation; and assumes that adults are capable of learning, changing, and acting to transform their own reality. Participatory action research also aims to improve the lives of those involved in the research process (Travers, 1997).

Inherent to a participatory action research approach are: the use of mixed methods to answer a range of different questions of interest to different participants in the project; active involvement from the community in all aspects of the research, including design and analysis; continuous feedback loops as emerging research findings are applied to elements of the intervention; and periodic review of the conceptual framework, design, and methods. Both quantitative and qualitative methods will be used. Qualitative methods are ideally suited to health research that explores relationships between culture, social factors, and health behaviours; triangulation with quantitative methods is increasingly being recognized as valuable in epidemiology and health services research (Pasick, 1997).

Project design and methods (as proposed in October, 2001)

This community capacity building approach involves an integrated partnership among four key players: a Community Health Centre (CCHC); a Latin American women's health group (LAZO), community-based researchers (Gentium), and university-based researchers (CHRU); and includes participation from the broader community through an Advisory Committee with representation from health professionals; cancer screening organizations; public health; women's research experts; immigrant settlement organizations; and other ethnocultural minority groups. Lay Health Promoters (LHP) will be trained to reach Hispanic women in their own communities, addressing cultural and linguistic barriers to breast and cervical cancer screening, in the context of preventive health care education for women. The LHPs also become participatory researchers, and assist in the design and implementation of the research component of the project. Qualitative and quantitative methods will be used to document the barriers experienced by Hispanic women; the effectiveness of strategies used to overcome these; the process of lay health promotion/community capacity building; changes in health knowledge and screening practices of women participating in the program; and health services offered to Hispanic women.

The demonstration project uses a community capacity building approach employing participatory research methodologies. The advantage for using such an approach is that involvement from the target population, for this project Spanish speaking women and health service providers, into all data collection mechanisms, analysis, and program implementation is sought at all stages of the project. The research component includes in-depth qualitative interviews and focus groups to document the building of community capacity; a case study at the organizational level analyzing barriers and strategies used at one community health centre to overcome these; and incorporates pre- and post intervention measures of knowledge, attitudinal and behavioural change at the individual level. This multiple level intervention is aimed at changing individuals, organizations, and communities.

Justification:

Benefits for building community capacity to improve access to preventative health services for underserved communities are:

- greater capacity and level of expertise within the minority community to promote preventative health care
- increased capacity of the minority community to work together with mainstream health care services
- greater capacity of health service providers and their organizations to serve ethnoracial minority women

Specific to this project:

- LAZO has begun a process of developing leadership skills for women from their community and attempting to bridge gaps between isolated women and health service providers.
- Centretown community health centre has a positive working relationship with LAZO and recognizes the need to focus on this underserved community.
- Gentium Consulting has experience with participatory, qualitative research with and about immigrant women, as well as applying a capacity development approach to program evaluation, and was approached by LAZO and CCHC to provide assistance to this project.
- CHRU provides solid background in community health research design and qualitative analysis, as well as transfer of knowledge and dissemination strategies.

Additional challenges and reasons for using descriptive and qualitative data collection methods, such as case studies, for this type of research are:

- lack of routinely collected statistics on ethnicity in relation to cancer incidence or mortality (Cancer Care Ontario, Canadian Cancer Registry, personal communications)
- difficulties in making comparisons between and within ethnic groups and immigrant groups (Estable & Meyer, 95).

According to Markland and Turnbull (93) a more rigorous framework of analysis, therefore, is needed to explain ethnic differences in cancer: "Detailed case studies are required to better understand the linkages between culture, ethnicity, social support mechanisms, structural inequality, health status, and cancer mortality" (p. 66).

Currently, a research project by Prairie Centre Women's Health Centre (Bowen and Garcia, 97) on overall health status and strategies of Salvadoran refugee women, confirm the importance of using qualitative and participatory methods very acceptable to the target Hispanic community. A Similar project seeking to understand health attitudes of South Asian women living in Canada (Bottoroff et al, 98) makes suggestions about how to structure health promotion strategies: paying attention to language used to talk about breast cancer and traditions for information sharing and advice - similar to the proposed model using LHPs from same communities/backgrounds to deliver health promotion messages.

Data collection and analysis

Quantitative data will be collected through:

- program documentation of intervention activities (e.g., LHP files, attendance reports at workshops and events)
- culturally-sensitive Spanish-language forced-choice format written survey instrument, based on Pathways (Hiatt et al, 1996) core questions on breast cancer and cervical cancer screening for Latinas, administered to women (16+) participating in the demonstration program
- file review at CCHC
- addition of mother tongue question to standard intake/visit forms at Ontario Breast Screening Program - Ottawa Centre Clinic, and subsequent file review.

Baseline will be collected on several ethnocultural client groups, permitting the eventual analysis of baseline information for other cultural/linguistic populations in future. By including mother tongue data at intake, the OBSP will also be able to monitor change in accessibility over time, through periodic review in future.

Quantitative data will be compiled and analyzed using SPSS. Standard statistical measures will be applied to determine direction and extent of the change in the total numbers and percentages of Hispanic women receiving services post-intervention, compared to baseline.

Qualitative data will be collected through in-depth interviews, focus groups, participant observations, practice logs, as described in original proposal.

Sampling technique, size, and timing

It is estimated that 1,000 women will participate in the demonstration project. A 20% sample (estimated: 200) of all women receiving the intervention will be surveyed.

A sub-sample of 50 Hispanic women will also participate in in-depth interviews; 25 of these will be age 50+. This is a purposive sample, and will include both women who have and who have not had mammograms, Pap smears, and regular care from a physician or nurse practitioner. Recruitment will be ongoing for a three month period,

and concurrent with interviewing, to permit periodic assessment of the distribution of the sample, and consequent adjustment.

Baseline data will be collected on mother tongue, age, and Well-Woman Check-up status of all CCHC primary care clients who received primary health care services in the year 2000, from system files; again, in 01 and 02.

Baseline mother tongue data also will be collected on all women receiving breast cancer screening (including mammograms) at the Ontario Breast Screening Program between April and September 2001; and in 2002.

Thirty health service providers (community health centres (nurses, nurse practitioners, and physicians), mammography clinics, family physicians, public health nurses, community developers and health promoters) will be interviewed in two focus groups (15 participants each) to identify service barriers and document current practices, pre-intervention. Data will be collected through audio tapes and written notes (details in original proposal)

Fifteen Advisory Committee members will be interviewed post-intervention. Open-ended, in person interviews will be audiotaped (details in original proposal).

Criteria for inclusion of women in the study

Criteria for inclusion in the research study are:

- female
- Hispanic (mother tongue Spanish)
- 16+
- capable of giving informed consent (consent documents translated/presented verbally if needed)
- currently living in the City of Ottawa.

Recruitment

Multiple methods will be used to recruit participants. The active involvement of the Hispanic community, and the participatory methods used in both the intervention and the research, are expected to yield positive results. Recruitment of a marginalized population is always challenging, and is anticipated to take place on an ongoing basis over many months. Outreach to the Hispanic population to participate in project activities will be concurrent with recruitment to participate in the research aspect of the project. Participants in project activities will be invited to participate in the research aspect of the project at first contact (first home visit, attendance at workshop or information session) through Lay Health Promoters, for both survey questionnaire and in-depth interviews. If interested, further information will be provided, confidentiality will be discussed, and consent will be obtained.

Demonstration of change in behaviour (not only knowledge, attitudes)

Data on screening behaviour, pre- and post-intervention, will be collected from interviews and from surveys with individual Hispanic women participants in the project. As described above, the TTM model permits analysis of data on stages leading to action in relation to health behaviour, at an individual level.

Comparison of screening data (post-intervention with baseline) at OBSP Ottawa clinic will demonstrate the effectiveness of the intervention in increasing the numbers of Hispanic women who sought breast cancer screening services.

Comparison of Well-woman Check-up data (post-intervention with baseline) at CCHC will demonstrate the effectiveness of the intervention in increasing the number of Hispanic women who receive cervical cancer screening; clinical breast examination; and teaching on breast self-examination.

Standard instruments used to survey individual Hispanic women include items assessing cancer screening behaviour (e.g., Mammography:- ever heard about mammogram;- ever read anything about mammograms [in own language; in English]; - ever referred to get a mammogram; - ever requested mammogram; - ever had mammogram; - had mammogram within last year; - had mammogram more than one year ago; - number of mammograms within 5 years), as well as attitudes and knowledge.

Outcome measures (proposed in October, 2001)

	April 1, 2001 - March 31, 2002	April 1, 2002 - March 31 2003
Measures: baseline	<p># of Hispanic (H) women screened for breast cancer and cervical cancer during the first 6 months at CCHC</p> <p># of ethnoracial women screened for breast cancer and cervical cancer during the past year at selected CHC and cancer screening centres</p> <p># of mammograms performed at clinics in O-C for H women and other linguistic groups in the first 6 months (40-49 and older than 50)</p>	<ul style="list-style-type: none"> • comparison of baseline data and follow-up data about level of cancer screening after 12 months of Ss women and other ethnoracial minority women • comparison of # of mammograms performed after 6 months and 12 months
Outcome measures: quantitative	<p># of women who completed LHP training successfully (according to assessment criteria)</p> <p># of H women reached by LHPs</p> <p># of H women previously screened prior to outreach</p> <p># of H women practicing regular BSE</p> <p># of organizations involved in the Advisory Committee (AC)</p>	<p># of H women reached by LHP</p> <p># of H women who attended health workshops delivered by health promoters</p> <p># of H women who report appropriate screening at follow-up</p> <p># of H women practicing regular BSE</p> <p># of organizations involved in the AC</p> <p># of meetings attended by each AC</p>

	# of meetings attended by how many organizations # of cancer prevention sessions held with H women # of training workshops held with LHPs	member # of ethnoracial organizations who participated in the community forum presenting results from demonstration project
Outcome measures: qualitative	<ul style="list-style-type: none"> • barriers identified by H women • perception of service providers of existing barriers to cancer screening for minority women • satisfaction with training by LHPs • satisfaction and impressions by key organizations participating in this project 	<ul style="list-style-type: none"> • satisfaction of H women with cancer screening information received from LHP at follow-up; • satisfaction and experience of H women accessing screening at follow-up • issues and experiences of LHPs doing outreach to H women • perception of service providers about project success
Process measures	<ul style="list-style-type: none"> • degree of commitment towards this project by participating organizations • readiness to move from entry phase to mobilization phase, according to capacity building model • readiness of key organization to work together on joint programs according to capacity building model 	<ul style="list-style-type: none"> • sustainability of working relationships of key organizations to improve cancer screening for ethnoracial women in Ottawa-Carleton • sustainability of LHP positions within health service delivery system • transferability of model to other ethnoracial minority communities

Evaluation Plan (October 2001)

The evaluation for this project involves both process and short-term outcomes. The impact of a project of this nature in reducing cancer mortality is long-term; evaluation of this type of outcome is not feasible within the timeframe of this project.

- a) Participatory methods provide a mechanism for ongoing evaluative feedback about project implementation which can be translated directly into practice or research design (formative evaluation).
- b) Outcome measures are built into the project at specific milestones/stages, to collect information on the degree to which project goals are achieved and research questions are answered.

Following a participatory methodology, the evaluation will be conducted by the project team and the Lay Health Promoters.

Evaluating the effectiveness of this type of intervention is recognized as challenging: outcomes are expected at several levels and different times; the type of change being sought is frequently continuous, rather than discrete; there is considerable interaction between components; and medium- and long-term effects may not be captured during the (funded) lifetime of a project.

The outcomes of the intervention (as expected in October, 2001) are anticipated to be:

At the individual level,

- to increase the knowledge, skills, and self-reported breast and cervical cancer screening behaviours of 50% of the Hispanic women who participate in the project activities
- to increase the knowledge, skills, and capacity to provide health promotion activities of 100% of the Lay Health Promoters

At the organizational level,

- to increase by 33% the number of Hispanic women who receive Well-woman Check-up at CCHC
- to increase by 25% the number of Hispanic women who are screened for breast cancer at the OBSP Ottawa clinic
- to increase by 50% the number of health promotion activities in Spanish, related to women's health (including cervical and breast cancer screening) that are sponsored by/held at the CCHC and its LHPs;
- to increase by 25% the numbers of Hispanic women who attend CCHC activities

At the community level,

- to move organizations involved by at least two further stages towards sustainability in the capacity building model (see attached schema)
- to have one other ethnocultural minority community at Stage 3 in the capacity building model
- to disseminate results of this project, and suggestions for transferability, to three other ethnocultural minority populations in Ottawa, through a community workshop
- to disseminate results of the research to community and women's health researchers and interested organizations/institutions
- to increase the number and density of community networks among organizations working on women's health issues; organizations of Hispanics and other multicultural populations; organizations that provide cancer screening services; and organizations that provide health promotion services
- to increase the number of media reports in Spanish related to breast and cervical cancer screening
- to increase the availability of culturally-appropriate Spanish-language information materials related to breast and cervical cancer screening at the OBSP, Ottawa Health Department, CCHC, and other community health centres.

What will be evaluated (as proposed in October, 2001)?

Project component	Evaluation method	Success indicators
Implementation of lay health promoter training	<ul style="list-style-type: none"> written and verbal feedback assessment of knowledge and skills 	<ul style="list-style-type: none"> level of satisfaction level of LHP's knowledge and skills
Outreach to H women by LHP	LHP logs	1,000 women reached
Cancer screening for H and other minority women	survey at CCHC, OBS, and other sites	increased # comparing data at pre- and post intervention
Community capacity building	interviews with AC members, LAZO, CCHC	level of stage reached according to indicators of the community capacity building model
Accessibility	<ul style="list-style-type: none"> interviews with H women, LHP logs participant observation 	reports of increased satisfaction with services; removal of some barriers identified pre-intervention
Dissemination of research findings	<ul style="list-style-type: none"> participant feedback during community workshop on research results review of media reports reports from project team members 	<ul style="list-style-type: none"> # participants involved in workshop # publications, articles # materials prepared in Spanish for public # conferences, presentations

At the end of the intervention, data will be collected on the cancer screening behaviour of Hispanic women (at CCHC, OBSP), and stage of community capacity of organizations involved, or for comparison with baseline and pre-intervention data on screening behaviour and community capacity. (See [key findings](#) for updated results).