A Healthy Balance

A community alliance for health research on women's unpaid caregiving

Equity Reference Groups
February 20 and 21, 2003
Halifax, Nova Scotia
Report

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Healthy Balance Research Program

The Atlantic Centre of Excellence for Women's Health (ACEWH), Dalhousie University and the Nova Scotia Advisory Council on the Status of Women (NSACSW) are providing leadership in the form of an innovative and collaborative program of research to better understand the connections between women's health and well-being, family life and earning a livelihood. The **Healthy Balance Research Program** (HBRP) is funded by the Canadian Institutes of Health Research (CIHR); other principal partners include the Family Caregivers Association of Nova Scotia, IWK Health Centre; Mount Saint Vincent University, and the National Centres of Excellence for Women's Health Program.

It is well known that throughout their adult lives, women are more likely than men to experience stress and overwork as a result of their multiple care and work responsibilities. There is uncertainty, however, about possible health benefits to women in the paid workforce. We are only beginning to understand the extent and nature of women's unpaid caregiving work and its stress and health impacts -- whether this caregiving work is done on its own or combined with paid work.

This innovative partnership program will improve our understanding of the ways in which caregiving is now organized (e.g., unpaid caregiving shared between women and men), how caregiving affects people's sense of empowerment in their lives, and, in turn, how that affects their health and well-being. Researchers will study different kinds of unpaid caregiving in Nova Scotia and will determine which unpaid caregiving situations -- on their own or combined with paid work are associated with positive or negative health. The program will also examine how social and economic factors interact with paid work, caregiving, empowerment and health status -- for example how ethnicity, race and culture, as well as rural and urban location, income, age of the caregiver and other factors affect the health and well-being of care providers in Nova Scotia. On a practical level, the program will consider current policies and programs that address paid work and family life and how these can be improved.

The ultimate goal of this program is to foster a "healthy balance" between women's health and well-being, family life, and earning a livelihood. The interrelated and dynamic program objectives include knowledge generation, knowledge transfer and transformation, uptake of new ideas and practices, and strengthening research capacity. Specifically, we intend to: examine the relationship among health status, empowerment, and unpaid caregiving work (performed on its own or in combination with paid work); foster "uptake" of new ideas and practices in policies; promote innovation in programs and health-service delivery that reflects new insights into the values and expectations we bring to caregiving and paid work; and strengthen research capacity in Atlantic Canada by recruiting and retaining health researchers.

Equity Reference Groups

HBRP has made a commitment to include the perspectives of historically disadvantaged and under-represented groups through its four Equity Reference Groups (ERGs): African-Canadian women, First Nations women, immigrant women, and women with disabilities. The ERGs have a

powerful mandate to contribute to all aspects of the research program by recommending and approving culturally appropriate and respectful data collection methods and information sharing strategies in their communities. They have also accepted the challenge of facilitating the translation of research into better policy and practice.
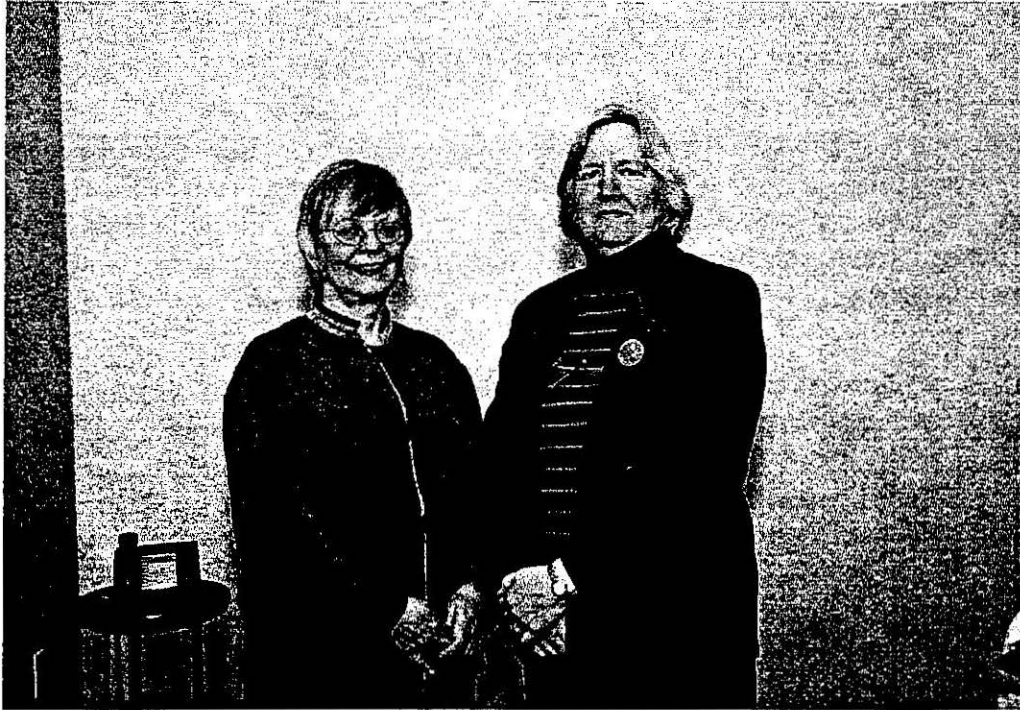
Brigitte Neumann and Carol Amaratunga
Healthy Balance Research Program Co-Directors

WELCOME AND INTRODUCTIONS

Brigitte Neumann, Executive Director of the Nova Scotia Advisory Council on the Status of Women, and Carol Amaratunga, Executive Director of the Atlantic Centre of Excellence for Women's Health, co-directors of the Healthy Balance Research Program, welcomed everyone and gave an overview of the two days we would spend together learning more about the Healthy Balance research. Brigitte introduced Susan Nasser, the new Coordinator. Susan asked participants to introduce themselves and reviewed the agenda. The list of participants can be seen in Appendix A and the agenda in Appendix B.

Susan then introduced Gail Bruhm.

FAMILY CAREGIVERS ASSOCIATION OF NOVA SCOTIA
Gail Bruhm, Executive Director

Gail Bruhm spoke to us about the Family Caregivers Association of Nova Scotia, FCgANS, a province-wide, not-for-profit organization dedicated to the recognition and support of family caregivers. Funding comes from the J.W. McConnell Family Foundation and the Nova Scotia Department of Health. FCgANS envisions a society where the contributions of caregivers are recognized and valued as a critical part of health care and where all caregivers are supported in this role. The Association strives towards this vision by offering the following services:

- ▶ up-to-date information on community, health care, and support services
- ▶ workshops, seminars, and support groups
- ▶ quarterly newsletter
- ▶ information packages that can be mailed

Upcoming initiatives include:

- ▶ Caregiver Summits involving employers - New Glasgow in March; Halifax in May
- ▶ funding for community-based projects
- ▶ a recognition luncheon for caregivers on May 16 - part of Caregivers Week

Gail addressed the issue of language, describing how she no longer refers to caregivers providing care for "loved ones" because she has come to realize that at times, caregivers are providing care for someone whom they do not love and may in fact have been in an abusive relationship with.

One of the issues that was highlighted at an international conference on caregiving held in Washington D.C., last fall was young people (children and teenagers) as caregivers. This is an area that FCgANS would like to explore further.

There was discussion about the concept of choice in assuming caregiving roles. Often, caregivers feel that they have been conscripted into providing care because of family obligations, societal expectations, and lack of alternate resources.

PRESENTATION BY TEAM Q - FOCUS GROUPS AND FOLLOW-UP DISCUSSIONS

Four members of Team Q (Charlotte Loppie, Katherine Side, Linda Bird and Laurene Rehman) joined us to talk about the conduct of the focus groups and to share some preliminary findings. The presentation can be found in Appendix C, details about the coding in Appendix D, and quotations from focus group participants in Appendix E.

Discussion Following Presentation

► The quotes are key to reporting on the focus groups; they enable readers to hear people's voices.

► Final report:

- written in plain language, language that is very understandable and accessible,

- not too long,

- catchy title,

- should be dictated to a cassette tape or CD so people with visual disabilities and those with limited literacy skills can access it,

- available on web site,

- hard copy should be accessible in design (e.g., a binding that allows for easy photocopying),

- **"Boiled eggs are easy"**...there was much discussion about this quote. Many of the participants found the quote 'said it all and 'hit home'. People thought that this quote would be a good title for the final report,

- nutrition emerged as a topic in many focus groups. Gail Bruhm, Director of Family Caregivers of Nova Scotia, said that during her many years working with caregivers, she had never heard this concern expressed. Thus, this particular finding is important. Not eating, as well as over-eating is an issue,

- in relation to the experiences of immigrant women, it was suggested that culture shock might play a factor in why some caregivers feel strained. This may be because they are coming to a new country, have no family here with them, and have to do everything on their own with no help/support from their own family. Different cultures have different expectations for women, different expectations of what the woman should be doing. It is also important to note that the impact of Canadian culture will vary depending on the woman's country of origin,

- the issue of control is a central theme - we should investigate possible sub-nodes. Formal home care situations were highlighted, where the recipient's home is the caregiver's workplace,

- other themes to consider: post-placement caregiving; intimacy, and care technology, in particular in relation to disabilities,

- important for caregivers to educate themselves about the care-recipient's condition as this will have an impact on the care provided. Caregivers often find themselves in a position of educating others as well,

- distinguish between short and long term care if possible.

Participants were given some questions to consider at the end of the presentation. On Friday morning these questions were discussed. These questions can be found in Appendix F.

#5   Care for the caregiver

#5 2   Self-care

#521	interactions with others
#522	humour
#523	sharing caregiving
#524	spirituality
#525	sharing experiences
#526	activities
#527	personal outlook
#528	me-time

- ▸ the categories are very broad; try to capture specifics
- ▸ there should be a place to highlight personal health practices - exercise, nutrition, and other relaxation/stress management options (see Gaps)
- ▸ fill-in care, get-away time, someone you can call on, the peace of mind of knowing you have someone to call on, are all important elements of self-care (see #6 - Gaps in care for the caregiver; Gaps)
- ▸ what about caregivers who do things related to their caregiving that decrease their own health, such as not eating properly (See #13 - Challenges of caregiving, Gaps)

#6   Gaps in care for the caregiver

- ▸ fill-in care, get-away time, someone you can call on, the peace of mind knowing you have someone you can call on - all could be coded as gaps if caregivers identify that they do not have them (see #5 2 - self-care, Gaps)

#12 Negotiating

#12 1 Balancing multiple roles

▶ emphasize role *conflict* related to paid work
▶ work environment - be sure to include all aspects

      ▶ large employer/small employer differences
      ▶ culture of the workplace
      ▶

See #13 6 - Challenges of caregiving - Job-related, Gaps)

#13 Challenges of caregiving

#13 1 Feelings and emotions

▶ there should be a well-defined category for feelings such as anger and resentment that call for more than coping (see Gaps)

#13 3 health

    # 13 3 1   stress
    # 13 3 2   sleep

▶ does "sleep" include fatigue, exhaustion? If someone said they were exhausted, would that be coded under sleep?

    # 13 3 3   illness and disease

▶ mental health of the caregiver should be specifically mentioned; this should not just be added in under "illness and disease"

#13 6 Job-related

▶ See also 12 1 - Negotiating/Balancing multiple roles, Gaps

****

▶ In general - what about caregivers who do things related to their caregiving that decrease their own health, such as not eating properly - sort of a negative self-care (See #5 2 - Care for the caregiver/Self-care, Gaps)

#16 Special challenges

- problems with the definition: *unique caregiving situations that fall beyond the normative experience*

    - What is meant by normative? Whose term is this - the researchers or the focus group participants?
    - What if participants did not recognize their experience as unique?

- Is this where disability issues are coded? Is this the only place where disability issues are coded?

- Is there some way to break down this category? It seems very broad, especially if it is where issues related to disability are being coded.

- What about women with disabilities who are providing care for other people. Are their experiences reflected here?

- How representative were the two disability focus groups? Were women with mobility disabilities well represented? (The overall percentage of participants identifying themselves as having a disability across all focus groups is 21.5% - the type of disability is not indicated.)

#17 Culture, race

- problems with the definition: *any culture, race or ethnic considerations the caregiver identifies as informing her/his caregiving roles and responsibilities*

    - what if there are considerations that participants are *not* aware of or are *not* able to articulate but which have an impact on their caregiving roles
    - racism and its impact on health is an example

- Is there some way to break down this category? It seems very broad.

Summary of Gaps

1. Putting a name to intense feelings such as anger and resentment, feelings with which caregivers may need in-depth help to sort through (See #13 1 - Challenges of caregiving/Feelings and emotions)

2. Role conflict, especially in relation to paid employment combined with caregiving responsibilities (See #12 1 - Negotiating/Balancing multiple roles, and #13 6 - Challenges of caregiving/Job-related)

3. Fill-in care (See # 5 2 - Care for the caregiver/Self-care, and # 6 - Gaps in care for the caregiver)

4. Behaviours that have a negative impact on the health of the caregiver, such as not eating properly (See # 5 2 - Care for the caregiver/Self-care, and #13 - Challenges of caregiving)

5. Personal health practices such as exercise, nutrition, and other stress management and relaxation options (See # 5 2 - Care for the caregiver/Self-care)

6. Food security is a distinct issue

   ▶ See #13 4 - challenges of caregiving/financial
   ▶ this could also be an issue of finding time to shop

Summary of definition problems

#16 **Special challenges**

   ▶ What is meant by "normative"?
   ▶ What if participants don't recognize their situations as unique?

#17 - Culture, race

   ▶ What if there are considerations that participants are not aware of or not able to articulate but which have an impact on their caregiving roles?

Discussion on communicating the findings of the research

What communities do you think need to get this information?

- ► Health clinics (e.g., North End Health Clinic)
- ► Equity Groups
- ► Separate presentations (especially for African Nova Scotian communities and others)
- ► Immigrant service providers
- ► Multicultural health associations
- ► Umbrella organizations (networks that already exist)
- ► Church groups
- ► Community health boards
- ► Major employers (e.g., government, insurance companies) - to address employment-related stress
- ► other employment related organizations (Chambers of Commerce, Boards of Trade, HRDC, unions)
- ► News conferences
- ► Conferences

What are the most appropriate ways to get the findings back to these communities?

Dissemination through local groups and networks would be most effective. The best way to support this sort of grass roots dissemination is to develop kits that facilitate local contacts to give speeches, make presentations, get an article in the local newspaper, etc. It was suggested that the Atlantic Centre of Excellence for Women's Health has some materials upon which such kits could be modeled.

PRESENTATION BY TEAM P - CAREGIVING PORTRAITS

Brenda Beagan, Team Leader, was not able to join us but sent along the following information, which was presented by Susan Nasser. Following the presentation, participants gathered in their specific equity groups to discuss a series of questions that Brenda had posed. The questions can be seen in Appendix F.

Brenda Began's presentation

I want to explore the **experience of caregiving**, making visible not just the physical work, but also the emotion-work, the thinking-work, the planning-work. What do caregivers actually *do* to make the giving of care happen? How is that doing affected by differences among caregivers, in terms of culture, ages, abilities, class background, location, relationships?

In particular, I want to explore the ways in which caregivers experience tensions, especially **ethical tensions or moral distress**. I'm thinking about those situations where you know what ought to be done, what needs to be done, but it's impossible because of various barriers. Maybe resources, money, support etc. Or situations where you are not sure what should be done, because to do A or B may have negative consequences. Or situations where what needs to be done conflicts with some strongly held moral value or belief. The kinds of situations that cause caregivers to burn out, experience stress, give up, shut down, or cease to care. And I want to know what caregivers do to try to deal with, resolve, or ameliorate these tensions. How they try to strike a balance, maintain well-being.

Then I want to trace outward from the experience of that particular caregiver, doing concrete things, having real emotions, experiencing real tensions and distress, to ask **why does it happen this way**. What social institutions, organizations, systems, policies cause that caregiver to have the experiences she has? What is it about the health care system that affects her? what is it about the labour force? the education system? social services? What shapes the caregiving experience to be the way it is? What are its determinants?

Research Questions:
What is the experience of caregiving in the home or within families like? What do caregivers actually *do* to make the giving of care happen?

How is the doing of caregiving affected by differences among caregivers: culture, age, abilities, class background, geographic location, relationship to care recipient?

Where do caregivers experience ethical tensions or moral distress? How do they attempt to resolve these tensions?

How are the experience of caregiving, and the tensions that may arise, shaped by social institutions, organizations, systems, and policies? What shapes the caregiving experience to be the way it is?

Research Methods:
Micro-ethnography: For each family/household, RA makes contact, explains research, gets consent. RA 'hangs out' for a while, participating, observing. About 24 hours total, over maybe a month. Something like 6 four-hour sessions. (Time to transcribe and analyze between sessions). During those visits, RA conducts interviews with caregivers, care recipient, possibly others. Minimally three recorded interviews with caregiver. Interviews focus on the experience of caregiving: what is actually done, its meaning to the participants, time, emotions, relationships. Subsequent interview focuses on ethical or moral dilemmas that arise for participants. Subsequent interview focuses on policy, systems, institutions that structure caregiving experiences.

<u>Photo-documenting</u> of the caregiving experience: Each caregiver is given a digital camera, and asked to take photos that capture her experience. At some point the camera is wielded by the care recipient for a while, to capture that standpoint. Photos will be an entry point for a subsequent interview, as the participant explains what each photo signifies.

Design parameters:
12 families/households
    2 African Nova Scotian
    2 Aboriginal Nova Scotian
    2 Immigrant/refugee
    2 Women with disabilities
    2 Gay/lesbian
    2 Rural, White, Heterosexual

Each ERG gets only 2 households to 'represent' them. We must remember this research is NOT intended to be representative; it is intended to seek depth. We won't pretend to know everything about what caregiving looks like in any community – the point is to really 'get' what it's like to *live* the experience for these 2 households.

I will want team members from each of the represented communities. Either academics with research experience, or people with expertise in policy analysis, or familiarity with the caregiving experiences in their community. Already on the team: Robin Stadnyk (Occupational Therapist), expertise in policy impact on elderly community-based caregivers. She has also suggested a First Nations woman who is a health policy analyst who may be interested in being on the team.

I will need one RA each from African Nova Scotian, Aboriginal, and gay/lesbian communities. Probably also one from the immigrant communities, one from communities of people with disabilities. Each would research 2+ households.

PRESENTATION BY SURVEY TEAM

Janice Keefe, Team Leader of the Survey Team, talked with us about the survey and some of the dilemmas it presented. The presentation can be found in Appendix G.

Background information

-     18% of Canadians are providing care
-     Every year, there are 100,000 more people providing care
-     Of those providing unpaid care, 60% are women and 40% are men
-     Women are two times more likely than men to be in the group that provides 10+ hours/day of unpaid care

Survey instrument

The survey instrument currently consists of 27 pages and includes the following sections:

- ▶ Unpaid work
  - • help given and received
  - • elder care, child care, and care for those with disabilities

- ▶ Paid work
  - • includes self-employment
  - • Balancing paid work and caregiving
  - • How does work interfere with family as opposed to how does family interfere with work?
  - • Does employer encourage or discourage you leaving on short notice due to emergency?
  - • Do you miss business trips, educational training or other social events at work because you are not-able to get away over night or during the evening?

- ▶ Empowerment
  - • resilience and beliefs/attitude scale

- ▶ Stress
  - • role overload, different for everyone and some people cope better that others
  - • health

- ▶ Demographics
  - • culture, country, what group do you feel you belong to?

Methodology

The survey will be carried out on the telephone. Approximately 2000 households will be contacted through random digit dialing. A contract will be entered into with a company experienced in surveys of this type. The time it takes to complete the survey is a key factor in determining the cost of doing it. Once the length of the survey has been determined, companies will be contacted to submit bids.

Testing the survey instrument

Two methods of testing the survey instrument are being pursued:

- ▶ One member of each Equity Reference Group has completed the questionnaire and provided written feedback on language, terminology and content.

- The questionnaire is being conducted on the phone with volunteers from the research teams.

The survey takes a long time to complete on the phone - up to 40 minutes for those who have caregiving responsibilities. For this reason, people need to be hooked into taking the survey. It needs to sound appealing to the individual from the beginning. Participants need to be told from the beginning how long the survey is going to take.

Discussion following the presentation

The discussion focused on two themes:

The length of the survey and the difficulty of convincing people to participate

Suggestions included

- Ensure that the explanation given by the caller is written in such a way that it encourages people to participate;
- Send a letter describing the survey before calling; include a small item such as a fridge magnet as an enticement. A letter that mentions Healthy Balance and the universities provides credibility to the survey. This strategy is not possible with random digit dialing. It could be altered to fit the random digit dialing realities - respondents who are located through random digit dialing could then be sent a letter and receive a follow-up call to complete the survey (or to say that they will not complete the survey);
- Organize a media blitz about the survey before starting, including a press conference describing the survey. People might be more inclined to participate if they have heard about the survey;
- Complete the survey in two sessions - neither session would be too long
- At the time of the first phone call, inquire whether this is a good time; if not, set another time for the caller to call back. Alternatively, let the respondent return the call at a time that is convenient for her/him;
- Have two versions of the survey - a short version and a longer version. If the respondent is not willing to complete the longer version because of time constraints, they should be asked if they have time for the short version.

The dilemma of doing a population-based survey, which relies on a random sample, while taking into account the representation of respondents from the equity groups

- Particular telephone exchanges can be targeted if there is an identifiable geographic community of members of an equity reference group. While the sampling within that telephone exchange could be random, the overall sample is not random. As well, some equity groups do not have identifiable geographic locations.

- There could be different approaches to encourage representation from the equity groups. For instance, a contact person could distribute questionnaires through community organization and gathering spots. The problem with this is that the data obtained has to be clearly recognized as different from the data from a telephone survey. Respondents would self-select and would be completing the survey in writing on their own, not on the telephone, where prompts and explanations can be given.
- If special efforts are not made to capture the issues of the equity groups, their voices will likely be lost in the overall survey because their numbers are so small within the general population.
- One strategy is to develop additional research proposals that will be structured to obtain the desired feedback from equity groups.
- It is important to remember that the survey is just one component of the Healthy Balance research. Findings from the other components - the focus groups, the secondary analysis and the caregiving portraits - could provide avenues for highlighting the issues of particular relevance to equity groups.

CLOSING COMMENTS

Susan led a brief discussion of how the meeting had gone. Participants felt it had been productive, but would have appreciated an agenda in advance. The two-day format was popular, and it was agreed to plan upcoming meetings using the same structure. Susan thanked everyone for their energy and enthusiasm during the discussions.

Summary of Feedback from Written Feedback Forms

The feedback form can be found in Appendix I.

Participants had overall positive comments about the organization, visual aids, format, pace and facilitation of the meeting and the presentations. They enjoyed the informality and having plenty of time for discussion and feedback. The thorough updates on the research were appreciated, as was the opportunity to grapple with the challenge of ensuring that the equity groups felt represented in the research. The informative presentation by the Family Caregivers Association of Nova Scotia was helpful.

Participants liked the visual aids, such as the coding tree and the timeline.

There were positive comments about having all of the ERGs meet together as this allowed them to hear from women with varied backgrounds and experiences. This approach fostered respectful, quality conversations among equals, dismantling a more traditional hierarchy between researchers and subjects.

The opportunity to ask questions after the presentations and the small group discussions created an interactive environment. Several participants connected their own experience as caregivers to

the discussions at the meeting, commenting on the benefits of talking together as a way to relieve stress and combat isolation.

It was suggested that the next ERG meeting use a similar two-day format so that the same unrushed atmosphere could be reproduced. Participants enjoyed having dinner together as a group because of the opportunity to talk informally with other ERG members.

While the facility was suitable, some felt that the meeting room was too far from the hotel guest rooms for those with disabilities. Although the room set-up, with no podium, created a comfortable atmosphere conducive to exchange and discussion, some found the noise level and the room temperature problematic.

Participants found the meeting well organized and well facilitated.

Susan Nasser, HBRP Co-ordinator, with
Patricia LeBlanc and Marcie Shwery-Stanley,
Women with Disabilities ERG Group

APPENDIX A

Equity Reference Group Members

Aboriginal

Denise Moore
Carla Moore
Barb Oke
Nancy MacDonald

African Canadian

Doreen Paris
Yvonne Atwell
Josephine Etowa
Sue Edmonds

Immigrant

Evangelia (Evie) Tastsoglou
Youmei Chen
Claudette Legault
Maria Yax
Shanthi Johnson

Women with Disability

Patricia LeBlanc
Marcellina (Marcie) Shwery-Stanley
Catherine Campbell

ERG Meeting Agenda

A Healthy Balance
A community alliance for health research on women's unpaid caregiving

Atlantic Centre of Excellence for Women's Health

Nova Scotia Advisory Council on The Status of Women

Equity Reference Group Meeting AGENDA

Thursday, February 20

12:00 - 1:00 p.m.	Lunch
1:00 - 1:30 p.m.	Welcome and introductory comments
1:30 - 2:45 p.m.	Gail Bruhm, Family Caregivers Association of Nova Scotia
2:45 - 3:00 p.m.	Nutrition break
3:00 - 5:00 p.m.	Team Q (Focus Groups)
6:00 p.m	Dinner at the Symposium - we hope you can join us!

Friday, February 21

8:30 - 9:00 a.m.	Gather and coffee
9:00 - 9:30 a.m.	Reflections on Team Q presentation
9:30 - 10:30 a.m.	Family Portraits - presentation and reference group-specific discussions
10:30 - 10:45 a.m.	Break
10:45 a.m.- 12:00 p.m.	Survey
12:00 p.m. - 1:30 p.m.	Working lunch/wrap-up

Team Q PowerPoint Presentation

Team Q
Update to ERGs

Healthy Balance Research Program
Feb. 20/03

Welcome to Team Q's Update!

- Agenda:
1. Introductions & overview to Team Q
2. Thank you for your ongoing involvement
3. Overview of process to date
4. Follow up feedback session
5. Questions & discussion

Project Review

What is "Team Q's" task?

To invite diverse groups across Nova Scotia to talk about caregiving in the context of their lives and their health.

Review – Summer/Fall 2001

- **Formed the Research Team**
  - Dalhousie, Mount St. Vincent, University of Waterloo
- **Developed selection criteria and question guide**
- **Met with Equity Reference Groups**
  - Participated in recruitment strategies, development of focus group guide, ongoing consultations
- **Hired a Focus Group Coordinator**

Review – Winter 2001/2002

- Received ethical approval
- Finalized selection criteria
  - Five (5) groups of those who care for children with and without disabilities, elderly, adults with disabilities or those with HIV/AIDS.
  - Thirteen (13) groups of caregivers who represent : Black women , First Nation women, immigrant women, women with disabilities, rural women, women living in conditions of low-income, female lone parents, elderly caregivers, men caring for a friend or family member.
- Invited community facilitators to begin recruitment of focus group participants

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Review – Spring 2002

- Pilot tested the focus group guide
  - Feedback was used to refine process and focus group guide
- Recruitment of participants from all groups
- Focus groups conducted between March and June 2002

Team Q Time Lines

Data collection completed

Data Analysis ongoing

Written Report summer 2003

Dissemination fall 2003

Knowledge uptake/translation
2003-2006

Detailed Timelines

- Transcription of focus groups – July – Oct. 2002
- Hiring of data coder – Nov 2002
- Development of coding "tree" & definitions – Nov – Dec 2002
- Preliminary data coding – Nov 2002 – Jan 30/03
- Secondary data analysis - ongoing

Major themes & methodological issues

- Presentation of code "tree"
- Discuss methodological issues
- Culture and "special challenges"
- "Best Practices"

Questions and Comments?

Do you see your care giving experiences reflected in the tree?
Have you identified any possible gaps?

Feedback & Uptake

1. Do you see aspects of your own care giving experiences reflected in the tree?
2. What communities do you think need to get this information?
3. What are the most appropriate ways to get the findings back to these communities?

Feedback and Uptake

4. Would you be interested in being part of the dissemination planning to get this information back to the various communities or stakeholders?
5. Do you have any other questions or issues about the process of analyzing the data?
6. Would you be interested in reviewing the preliminary findings and providing feedback?

Questions & Discussion

Reminder regarding feedback

- Susan Nasser will spend ½ hour with you tomorrow morning to go over any other questions or feedback you may have for TEAM Q
- You are invited to take a feedback sheet with you tonight and fill it out
- Both verbal and written comments are welcome

THANK YOU ALL FOR YOUR CONTINUED SUPPORT AND GUIDANCE!!!

APPENDIX D

TEAM Q - CODING THE DATA FROM THE FOCUS GROUPS
PRESENTATION BY LINDA BIRD

*** Please note: This presentation explains the coding process, highlights some methodological issues, and introduces preliminary findings from the data. There is still a great deal of analysis to be done.

Introduction

I hope you all have had an opportunity to look at the tree on the wall and read some of the quotes coded to each node to give you an idea of what types of things were coded or stored at each of the nodes. There is a list of nodes and definitions there as well if you would like to explore it in more detail. Before I begin it is important to remember that all of us as caregivers have our caregiving experience shaped and influenced by multiple different factors in our lives. This tree represents the major themes affecting caregiving experiences that emerged from the focus group transcripts. As an individual caregiver, not all the themes will have the same relevance in our individual lives. The tree represents an aggregate of the themes and issues emerging from all the focus groups conducted for this project.

In today's session I am going to explain my role in the project and how we go through the process of analysing the focus group transcripts. Please ask questions at any time. ·

Presentation of code "tree"

- There were 17 interviews and we began with a simple tree of major themes that were agreed upon in discussions with team Q members. The major themes or nodes emerged from the Focus group guide and from the voices of the participants as they shared their caregiving experiences. Team Q also discussed and agreed upon a definition for each node so that we all shared the same understanding of what would be coded to that node.
- The tree continues to change as we work with the data. To date, after the first preliminary coding of all 17 focus groups, there are 91 nodes (nodes and child nodes equivalent to branches and twigs). Include themes such as **Gender Expectations**, Transition to caregiving, **Care for the caregiver**, Gaps in care for the caregiver, Resources available, **Need for resources**, Attitudes from others, Isolation, **Urban rural issues**, Negotiating, **Challenges of caregiving**, **Future policy considerations**, Special challenges, Definition of caregiving, traits of the care receiver.

- As I work through the interviews, some of the themes needed to be broken down into smaller units (child nodes). **Example**: Attitudes from others:
    Helpful:
    ...the pharmacist said to me months before "Anything you ever need when he started to die, we will get it to you - if you need syringes, whatever, you just phone us and we'll bring it."

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Hurtful:
Well, you're not raising my daughter...oh, they're a dysfunctional
family....a dysfunctional family to me is not...myself

But a lot of people don't classify a stay home Mom as working.

I think a lot of times people think because we live in the country we don't know anything.

- As I code, sometimes new themes become more evident and then new nodes need to be added to the tree.

  For example: Traits of the care receiver. This captures any comments that were made that link the care giving experience directly to the physical and mental qualities or abilities of the person receiving care.

  Sometimes when it's a good day, she's upbeat, going to school, everything's great, her sugar is down to 5.6, Mom stops calling, aunt ...has home care finally coming in, you think "It's a great day".

  Because I know quite often with my mother in particular, she's there by herself. I'll say mom sorry I'll have to leave you alone. She'll say, no I'm not alone, god is with me. It makes you feel good. You don't feel so bad for leaving.

  I remember my Dad making me feel unappreciated. That kind of made me ...doubt. Like I was doing my best trying to make him comfortable and cook for him, but I could never cook right.

  My daughter, she's young; I get frustrated sometimes. I want to help her so bad, but she just won't work with me.

  Our problem with Mom, is that she's deaf. So that takes its toll on us. It's either screaming at her, which we do, and that's probably not smart for us to be doing that because it's hard work.

  Caring for someone who is dying is horrendous. It's a big job.

- Often there are many themes embedded in a person's comments. Then we code the same text to many different nodes.

Any questions on the coding Process?

- **6 free nodes**- not part of the tree in the beginning but can be added to the tree(like a tree graft) or can sit outside the tree:.**Methodological Issues, Quotable Quotes, Paid caregiving**, For example- Free node of **Caring for pets**- didn't materialize into a major theme - would not add it to the tree. On the other hand **Control has emerged as a major theme and will be moved into the tree.** Methodological issues - things that arise from the process of conducting a focus group that helps us understand the process of collecting the data and as researchers helps us to look objectively to our role in the data collection process.

Discuss methodological issues
- Many of the focus groups brought together caregivers of a distinct community, however, even within each focus group there was great diversity (participants age and life experiences, number of people they were caring for, traits of the care receiver, resources available to them including support from family and friends, etc.).
- Each participant spoke of their caregiving experiences that has been affected by many different factors within and beyond their individual control.
  For example: Rural Urban issues. While there are some differences to accessing health care and other resources in rural communities, Social support seems to be more connected to an individual's relationship and support from family and friends.

  But you know, I don't think it is so much the fact that we're black women as it is that we're a small community. When you are a small community, everybody knows everybody. What happens in your life, you don't even have to relay it sometimes somebody already knows it. It makes the sharing aspect so much easier.

- Other factors can contribute to a caregiver's feeling of isolation be it rural or urban as the above conversation continues:

  But if you hadn't been out there in the beginning, you might not know what is available either. If you are not a person who is out in the community very much. We have people in our community who just don't know what is available.

- Another methodological issue concerns the process of facilitating a focus group. Some facilitators had more skill or experience facilitating and some groups were easier to keep on target. Sometimes a facilitator read off a question and all the prompts at once and then the participants may not have addressed all the issues. The following is one of my memo's:

  11:49 am, Jan 3, 2003. I have found that in many of the interviews- multiple questions are read off by the facilitator at the same time- the last question gets answered and the

*other questions get lost. for example- focus group X asks about stress **and** the positive impact of caregiving at the same time. It would have been better to ask about these issues separately.*

- The dynamics of a focus group make it harder for some participants voices to be heard. Sometimes a person's comments are not explored because the conversation goes off in a different direction.
- One of the positive methodological issues arising from the interview process was so many caregivers in the focus groups welcomed the opportunity to get together and share their experiences with one another.

I like this getting together, because you find out that you're not the only one, and there's some like...'would you like to trade this for that?' and not all the time.

You usually find out more about things from word of mouth.

I think we can learn more from these focus groups.

I'm really glad that it's research being done, so hopefully it will lead to some change and better services being available. HIV has led the way in shifting who community is and how we care for community, and it's taking the rest of the country a little more time to catch up and I think this kind of research will be very helpful in that public process, and also in the policy process.

Many times they offered support and gave helpful suggestions to one another.

Sometimes when you finish taking care of everybody else, all you want to do is to lay down somewhere and food is way down there at number 23 or something, not a priority.

Boiled eggs are easy.

- The act of memo writing- which is to attach my thoughts as I work through the interviews helps to capture both the differences and similarities among the diverse caregiving experiences. The act of putting your ideas down on paper (computer-keyboarding) helps you to reflect on what you are doing and how it connects with the broader issues.

12:15 pm, Jan 16, 2003. Added text 130-133 because it is a lovely example of how these women are baring their sole to one another and at the same time offering support- woman talking about how difficult it is at times to look after own nutritional needs and another woman recommends " Boiled eggs are easy".

Culture and "special challenges"

We have only just begun the more in-depth analysis of the focus group data. However, we know you are particularly interested to hear about issues relating to your specific group/community. Here are **a few** examples of issues arising from the focus groups.

Caregiving and cultural issues are inter-twined. Our perceptions and expectations of caregiving have been informed in part by the community we have grown up in and live in. One caregiver says:

> *Well I was raised in a black community and in a black community, everyone took care of one another. I think it is ethnic.*

And the same women reflects on her own comments and continues:

> *.... I think if we're truly Christians that the caregiving we are gonna give, whether we're in the black community the white community or whatever community because if you're a true Christian, you're going to give any way because that's part of what we're taught.*

There are cultural expectations informing care. One Aboriginal women comments:

> *Again, I know that in our culture, it's inherit. You look after your own folks, you look after kids, and whatever caregiving comes with that.*

Some of the caregivers voiced their frustration at the lack of knowledge by health care professionals to the every day care activities they are providing. An African Canadian woman comments:

> *One gentleman that comes in from Nigeria and another Black guy. I find that those particular ones are more apt to know which, they don't have a problem with combing his hair. The other ones won't touch his hair because it is different.*

Another women in the same focus group comments:

> *But you teach them that. Because the girls that come to my husband didn't know that. I had to say to them, this is the cream. It is important, but if we don't have the black workers to do it, you have to show them.*

This same type of frustration was voiced by Aboriginal caregivers:

> *It would be nice to have a native professional there for child care, someone that can relate to you more easily, which I believe would be another native...or adult care. That's what I'd like to see in the city, living here.*

I'm in a stage in caregiving that I don't care where it comes from. I would like to say I would like it to be native, but I really don't care as long as there is some help here somewhere. Diagnosis for ALS is two to three years after diagnosis, as life expectancy, so I'm on a last leg of whatever's here, so I can't wait for the idealistically native care. I need something a little quicker than that.

Throughout the focus groups caregivers spoke freely about their experiences and many were above and beyond the traditional caregiving role. Due to current changes in our healthcare system, many caregivers are taking on responsibilities and procedures that would have been done by a health professional in the past:

And her blood pressure has to be checked every week, and if that fluctuates then you know there's something going on...Now I take her blood pressure.

I had to learn how to give suppositories. After you do it once, there's nothing to it.

I care for my mother, she's diabetic. I give her 3 needles a day.

The stigma of diseases such as HIV/AIDS and some forms of mental illness can be an isolating factor for the caregiver as they may not seek help from others in an effort to protect the care receiver.

But when people are dealing with mental, it's always a taboo. People don't like for that to come out of the closet. They'd rather keep that in the closet so unless you can come out and seek groups and get doctors to be involved and open your mouth in discussions, you're gone.

Caring for individuals with disabilities or dementia creates special challenges. The unpredictability of illness such as dementia can be very stressful. One woman speaks about an experience she had with her father who was suffering from dementia:

It was March, his coat was there, so he went out without his coat. I phoned my neighbour and we went in cars, looking for him. My biggest fear was that he would take off in the woods. But we found him.

Caregivers with disabilities or health problems have their own personal challenges to cope with along with their role and responsibility as caregiver:

You do and you just go, go, go...just to prove that you can do it because that No. 1, you're a woman; No. 2 you have a disability.

If you already have health problems, like I have, arthritis and fibromalgia then you have to try to look after somebody else when you're sick.

I'm in my house 24/7 because that's where I work...because of the kids I can't run away. I'm also disabled; my kids who help me as far as what I miss in translation or somebody knocking at the door because I don't hear it.

Many of the caregivers from a range of focus groups were caring for an individual in the last stages of their life.

When you care for someone you know is going to pass away, you're doing what needs to be done, but when you're caring for someone who is just dealing with all this emotion - it's not like they're in and out of consciousness - so you deal with it on a daily basis and it's always bringing challenges they're running into you have to deal with - it's ongoing.

It's important to stress that it's the whole family who needs a break from death and dying and going on about it.

The caregiving experience of Immigrant woman may be further impacted by being in a different country of origin without many of their traditional supports of family and friends in the new country.

...when I moved to Canada, my experience was hard because I didn't have the language and because I didn't learn the Canadian system, I was feeling that I didn't have the same abilities as them, and skills. So I was feeling a little bit powerless, useless and because I couldn't provide the cares I should do, or the care I think I thought I should do, because I didn't have enough knowledge, enough understanding of the systems, and it as...stressful... and also because I don't have friends, my friends, my network, so I had to support that situation, I had to support her just by my own. So the stress of caring her in an unfamiliar environment without network, support network, was really, is really a frightening situation.

I feel I'm happy when I go to work because when you stay at home, when you come to Canada you don't have relatives, friends, some people to talk with them, it feels happy to meet some people from other cultures, and the children, the parents, the teachers, I am very happy with them because I feel that I am involved in the society.

Language and unfamiliarity with the Canadian system can be challenging for immigrant women:

And nobody come to you to tell you if you need services, for your new life.

For a social situation, maybe MISA is a great help, but for day to day situations for a newcomer, a person cannot speak English, don't know where should I go or what should I do.

One woman explains the challenge of finding day care so women can attend English class. Not being able to speak English affects their ability to get jobs.

How do we enter back into society? They will stay longer and longer at home because there are no places where they can take care of their kids, so we wouldn't have longer - to learn English is really slow - because they don't have the opportunity, because they have to take care of their kids.

Geographic distance to provide care for other family members with financial implications:

Also because financial...from your country or from Canada, the price so different. So I call them,

Caregiving and different cultural expectations between generations was also cited by some of the immigrant women:

What they meant was the children who were born in their original country, or they came with their parents as a toddler, a very young age...there are people I do find part of a culture shock so of course your children grow up, a different age. They have different interests, they have different concerns.....

The cultural expectations for women's roles may differ, however it depends on what country they are coming from and also may relate to their class system. In the following quote, one immigrant woman compares her life here with life in her country of origin:

I don't know about Canada, but in our country, the woman has to do everything for all the family. She has to. And it's hard. I'm relaxed here in Canada. Certain times I feel that I have to go to my country, but I'm relaxed here. I want to stay here for the rest of my life.

Another woman had the opposite experience:

...since I came to Canada, I learned how to be responsible for everything. By my self I have to raise my children with my own hand. All this I learned here in Canada.

Another woman comments:

Just a few months ago my mom was sick and we couldn't afford to go back to visit her, but in my culture I have to obey my husband so my husband forced me not to go.

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"Best Practices"

There are many other issues emerging from the data that could be discussed but we would like to focus now on the best practices that are emerging from the data. As caregivers, we are faced with many challenges as we try to meet our own needs as well as the needs of those we are providing care to. Caregivers are resourceful people and have developed strategies to help them deal with the sometimes overwhelming all encompassing role of caregiving. The following are just a **few** examples of the best practices caregivers embrace to meet their many roles and responsibilities.

I find when my mother calls me, I can enjoy that because I can bounce off of her, I can tell her what's going on in my life; she tells me what's going on with her life. Because my mother is not my mother, she's my best friend.

I can say I am very positive, I learned how to deal with me. This time, it's going to be about me. I'm taking my time and I'm going to spend these three hours for me and only me. Whatever comes up, sorry, but this is my time and my space.

And we'll gather on the phone and they'll pray with me and they will pray with my husband so all that stuff has impacted my personal life to know that there is other people out there going through the same thing.

At times I was afraid to leave my grandmother and go to church, so I had to speak to my church and in turn they came to my grandmother's building, and it wasn't like church, some of the members came to have some time with me, singing, prayer times, bible reading, and that was good for me. What it did was it empowered me, it gave me what I needed to continue, gave me strength and re-affirmed some things, and then there were friends supporting you, even while you were there doing your stuff.

We have elders who come in and talk to you and they're giving you all these things that I don't think a lot of us really pinpoint. You get counselling, they tell you stories about a long time ago, or when this happened to me when my wife was sick, or when I lost my son or my daughter, situations like that. It seems like these people come automatically, cause they know you lost a child and they say Gee, I lost a child too; maybe if I go visit them I'll give them the care and support they need. And these are the people that come, and they don't get paid from anywhere, they just come. They're kind of caregivers too, they're giving you the comfort and the emotional support you need.

I go to Alzheimer's meetings and I find them a support because unless somebody else is going through what you are...

I used to think that there was no body in the house that could provide for him. I found out when I went away for a week or so. But when I got back he was looked after and things were done.

Self-confidence and self-assurance. There's no other way you could get it. Those are such little words for what it is I'm trying to describe. I think probably it has more to do with spirituality, the spiritual side of self-confidence and self-assurance.

As you can see, these focus groups are rich in information and we appreciate everyone's efforts in helping to make these focus groups happen. The analysis is an ongoing process and we value your input. At this time we would like to ask you two questions (Questions- slide 10)

Do you see your care giving experiences reflected in the tree?

Have you identified any possible gaps?

APPENDIX E

Team Q Quotations

But that's what life is all about. Caring for your family. These are the important things in life.

My husband says doing the dishes every other couple of days, is contribution to woman's work. I don't think sometimes, the men appreciate what the women do.

I've been a caregiver for family members, for different times in my life.

Family and home care service, VON, clergy, church visitation.

Can't do without your friends.

Well you're not allowed to get sick when you're looking after somebody. Because nobody else is going to look after you, so you can't be sick.

There are many days where I would be more than happy to have someone take care of me for a change.

So you have to be able to understand, and you have to be able to read up on what's out there and what's new that can improve yourself as a caregiver as well as the person that you're giving it to.

The county does have some programs like recreation and leisure because they're into accessibility for everyone.

I have a room in one end of my house and I can't hear him if he needs something, so I have a bell.

You say about these resources here, but it's the same as an 8:30 - 5:00 day, what happens when you're in trouble after that? You get a recording.

I wish we had a chance, our natives, to have a chance to own their own house, even.

I think they started to appreciate what I was doing.

But a lot of people don't classify a stay home Mom as working.

For a year and a half I wasn't going out. They said oh my god girl it is so good to see you, I said I just didn't feel like it. I just didn't feel like I should leave him.

Living in this area definitely impacts, not so much on the ability of care that you can give, but on the resources that you have to help you.

You also have to do a lot of teaching, because people don't know. You have to make them aware of the illnesses that are going on within your families.

And gardening is good therapy.

It's really important that you don't give up your own self-things ... keep your balance.

Until the home care workers came in, I don't really think I totally understood how much of an impact it had on me physically. I knew that I was always getting through.

You grab what you can. You eat after everybody else.

Sometimes when you finish taking care of everybody else, all you want to do is lay down somewhere and food is way down there at number 23 or something, not a priority.

Social life, what's that?

At first my husband was home with her, but then she got to the point where she just depended on me, so I just gave up my work to always be there.

Take care of everything. Around the clock. Never having a break.
Oh yes, a lot of time to and from the hospital. A lot of time watching him wither away.

I know the day will come when I can't commit to taking care of him for rest of my life. I have my own needs.

They come first. You're always trying to protect them, you almost never think of yourself.

Oh, I feel good when I can help someone, no matter who I can go and help, I feel good about it.

And why should we have to have our teeth fall out just because we stay home and look after the kids.....

APPENDIX F

Questions to reflect upon
Team Q

Friday morning's session will start off with an opportunity to provide further comments on the emerging themes in Team Q's work and ways of making this information known in various communities.

The following questions will guide the discussion. We invite you to write down your answers or to share your thoughts during the discussion on Friday morning.

Thank you.

1.   Do you see aspects of your own caregiving experiences reflected in the tree?

2.   What communities do you think need to get this information?

3.   What are the most appropriate ways to get the findings back to these communities?

4.   Would you be interested in being a part of the dissemination planning to get this information back to the various communities or stakeholders?

5.   Do you have any other questions or issues about the process of analyzing the data?

6.   Would you be interested in reviewing the preliminary findings and providing feedback?

APPENDIX G

Team P - Questions for discussion by individual Equity Reference Groups

Questions for the African Nova Scotian ERG members

There will be only 2 African Nova Scotian households/families in this part of the study. Remember this research is NOT intended to be representative; it is intended to seek depth. At the end we won't know everything about what caregiving looks like in the African Nova Scotian community – the point is to really 'get' what it's like to *live* the experience for these 2 households.

How, then, would you like the team to select the 2 households from your community? A lot will depend on who is willing. But in an ideal world, what kinds of households from your community would you like to see participate? We could choose by rural/urban; type of care giver – care recipient relationship; typical or atypical care giving situations....

We are considering using photographs as part of the research. There's also talk about maybe video footage.... **To what extent do you think including photos would be acceptable in your community? Would it be likely to exclude people?**

To what extent do you think including a video would be acceptable in your community? Would it be likely to exclude people?

I'll need at least one African Nova Scotian research assistant. Any ideas? If not individual names, what kind of person folks in your community would be most comfortable opening up to? (Student, older retired woman, someone very like themselves, from their own community, or a different Black community...?)

I will want team members from each of the represented communities. Academics with research experience, people with expertise in policy analysis, familiarity with caregiving experiences in your community, help with access and recruitment... **Who do you know from your communities that would be a good addition to the team?**

Questions for the Aboriginal Nova Scotian ERG members

There will be only 2 Aboriginal households/families in this part of the study. Remember this research is NOT intended to be representative; it is intended to seek depth. At the end we won't know everything about what caregiving looks like in Aboriginal communities – the point is to really 'get' what it's like to *live* the experience for these 2 households.

How, then, would you like the team to select the 2 Aboriginal households? A lot will depend on who is willing. But in an ideal world, what kinds of households would you like to see participate? We could choose by rural/urban; on reserve/off reserve; type of care giver – care recipient relationship; typical or atypical care giving situations....

We are considering using photographs as part of the research. There's also talk about maybe video footage.... **To what extent do you think including photos would be acceptable in your community? Would it be likely to exclude people?**

To what extent do you think including a video would be acceptable in your community? Would it be likely to exclude people?

I'll need at least one Aboriginal research assistant. Any ideas? If not individual names, what kind of person folks would be most comfortable opening up to? (Student, older retired woman, someone very like themselves, from their own community, or a different First Nations community...?)

I will want team members from each of the represented communities. Academics with research experience, people with expertise in policy analysis, familiarity with caregiving experiences in your community, help with access and recruitment... **Who do you know from your communities that would be a good addition to the team?**

Questions for the Immigrant / Refugee ERG members

There will be only 2 immigrant/refugee households/families in this part of the study. Remember this research is NOT intended to be representative; it is intended to seek depth. At the end we won't know everything about what caregiving looks like in immigrant/refugee communities – the point is to really 'get' what it's like to *live* the experience for these 2 households.

How, then, would you like the team to select the 2 Immigrant/Refugee households? A lot will depend on who is willing. But in an ideal world, what kinds of households would you like to see participate? We could choose by rural/urban; country of origin; type of care giver – care recipient relationship; length of time in Canada; typical or atypical care giving situations…. (I'm particularly concerned about this piece of the research – the category 'immigrant/refugee' seems so broad as to be meaningless! I need help deciding how to set the boundaries.)

We are considering using photographs as part of the research. There's also talk about maybe video footage…. **To what extent do you think including photos would be acceptable in immigrant/refugee households? Would it be likely to exclude people?**

To what extent do you think including a video would be acceptable in immigrant/refugee households? Would it be likely to exclude people?

Would immigrant/refugee households want an immigrant/refugee RA doing the interviews? If so, would she have to 'match' the country of origin of the participants? Could the RA be White, or African Nova Scotian, or a woman with a disability? An international grad student (I have one coming in Sept from Japan)? A South Asian woman (I have an RA now whose family came to Canada when she was 15).

I will want team members from each of the represented communities. Academics with research experience, people with expertise in policy analysis, familiarity with caregiving experiences in your community, help with access and recruitment… **Who do you know from in immigrant/refugee communities that would be a good addition to the team?**

Questions for the Women with Disabilities ERG members

There will be only 2 households/families headed by women with disabilities in this part of the study. Remember this research is NOT intended to be representative; it is intended to seek depth. At the end we won't know everything about what caregiving looks like in households/families headed by women with disabilities – the point is to really 'get' what it's like to *live* the experience for these 2 households.

How, then, would you like the team to select the 2 households? A lot will depend on who is willing. But in an ideal world, what kinds of households would you like to see participate? We could choose by rural/urban; type of disabilities (physical only? Cognitive, psychiatric?); type of care giver – care recipient relationship; typical or atypical care giving situations....

We are considering using photographs as part of the research. There's also talk about maybe video footage.... **To what extent do you think including photos would be acceptable in your community? Would it be likely to exclude people?**

To what extent do you think including a video would be acceptable in your community? Would it be likely to exclude people?

Would women with disabilities want an RA who also has disabilities doing the interviews? If so, would she have to 'match' the disabilities of the participants? I know this sounds bizarre... But, for example, could an RA with mental health problems interview women with physical disabilities, or vice versa? Is the similarity sufficient to consider them members of the same 'community'? Any ideas for RAs?

I will want team members from each of the represented communities. Academics with research experience, people with expertise in policy analysis, familiarity with caregiving experiences in your community, help with access and recruitment... **Who do you know from your communities that would be a good addition to the team?**

Survey Team - PowerPoint Presentation

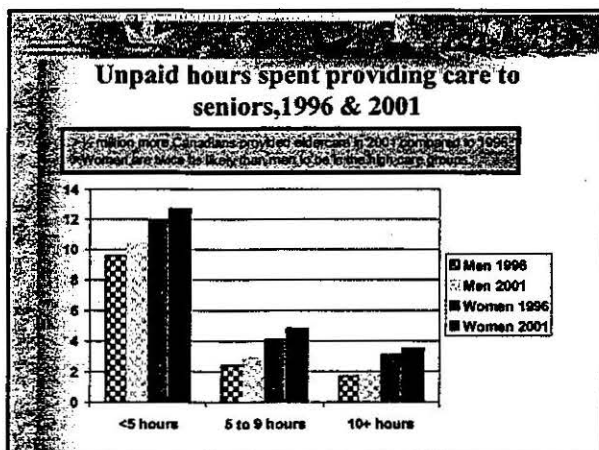## Phase 2: Comprehensive Population Survey

Feb 2003
Janice Keefe, Ph.D .
Mount Saint Vincent University

A Healthy Balance: a community alliance for health research on women's unpaid caregiving

Outline

- Goals of survey
- Survey development
- Components of survey instrument
- Current Issues
- Input from Advisory Committee

A Healthy Balance: a community alliance for health research on women's unpaid caregiving

Unpaid hours spent providing care to seniors,1996 & 2001

2 million more Canadians provided aid or care in 2001 compared to 1996. Women are twice as likely than men to be in the highest care groups.

Legend: Men 1996, Men 2001, Women 1996, Women 2001

X-axis: <5 hours, 5 to 9 hours, 10+ hours

Goal

- To provide insight into the scope of unpaid work

- To investigate perceived levels of empowerment

- To provide health outcomes related to unpaid work and caregiving

A Healthy Balance: a community alliance for health research on women's unpaid caregiving

Survey Development

- Compilation of Canadian referenced survey instruments
- Comparative analysis of question wording in each survey
- Completed survey being tested

A Healthy Balance: a community alliance for health research on women's unpaid caregiving

Components of Survey Instrument

1. Unpaid Work
2. Paid Work
3. Balancing Paid Work & Caregiving
4. Empowerment
5. Stress
6. Indicators of Health
7. Demographics

A Healthy Balance: a community alliance for health research on women's unpaid caregiving

Current Stage

- Feedback from ERG consultants?
  Aboriginals, persons with disability, African Nova Scotians & immigrants
- Feedback from pre-tests
- Contracting with survey ?
  - Marketing firm/in-house
  Balance between re-conceptualization of caring and comparability with past national based surveys

A Healthy Balance: a community alliance for health research on women's unpaid caregiving

Feedback ?
Questions?

A Healthy Balance: a community alliance for health research on women's unpaid caregiving

APPENDIX I

Feedback Form

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Healthy Balance Research Program
Equity Reference Groups
FEBRUARY 20 & 21, 2003

FEEDBACK FORM

</div>

1. What did you like *most* about the meeting?

2. What could have been improved?

3. What are some of the things you learned?

4. What are some questions you still have?

5. Do you have suggestions for the next meeting?

6. Should we use the two-day format again?

7. What do you think of the facility? (If you have a suggestion for a better facility, please let us know - we will be happy to check it out!)

8. Final thoughts?