UNCOVERING SEX AND GENDER DIFFERENCES IN USE PATTERNS OF SELF-HELP AND SUPPORT GROUPS

Annotated Bibliography
And Research Agenda

Robin Barnett

Project#116 of the Prairie Women's Health Centre of Excellence

UNCOVERING SEX AND GENDER DIFFERENCES IN USE PATTERNS OF SELF-HELP AND SUPPORT GROUPS
Annotated Bibliography and Research Agenda

Robin Barnett

November, 2005

Prairie Women's Health Centre of Excellence (PWHCE) is one of the Centres of Excellence for Women's Health, funded by the Women's Health Contribution Program of Health Canada. The PWHCE supports new knowledge and research on women's health issues; and provides policy advice, analysis and information to governments, health organizations and non-governmental organizations. The views expressed herein do not necessarily represent the official policy of the PWHCE or Health Canada.

The Prairie Women's Health Centre of Excellence
56 The Promenade, Winnipeg, Manitoba R3B 3H9
Telephone (204) 982-6630 Fax (204) 982-6637
Email: pwhce@uwinnipeg.ca

Robin Barnett
1156 Rose Street
Vancouver, British Columbia V5L 4K8
Telephone/Fax: (604) 255-5363
Email: rose2@telus.net

This report is also available on our website: <www.pwhce.ca>
This is project #116 of the Prairie Women's Health Centre of Excellence
ISBN# 1-897250-01-0

centres of excellence *for* WOMEN'S HEALTH

centres d'excellence *pour* LA SANTÉ DES FEMMES

Uncovering Sex And Gender Differences In Use Patterns Of Self-Help And Support Groups

Robin Barnett

TABLE OF CONTENTS

1.0 INTRODUCTION 3
1.1 Contents of this Report 5

2.0 DEFINITIONS 6
2.1 Definitions of Self-Help/Support Group 6
2.2 Sex and Gender 7

3.0 SEARCH 9

4.0 NATIONAL SURVEYS 11
4.1 Canadian Survey Data 11
4.2 U.S. Survey Data 12

5.0 OVERVIEW OF COMMON FINDINGS 14
5.1 Face to face self-help/support groups 15
A. Groups for men 15
B. Groups for gay men 16
C. Groups for women 16
D. Groups for lesbians 16
E. Transgender groups 17
F. Queer groups (mixed lesbian, gay, bisexual and transgendered or LGBT) 17
G. Mixed groups of men and women or gay and heterosexual 17

5.2 Internet Support Groups 17

6.0 RESEARCH AGENDA 19

6.1 What are the connections between gender and self-help/support groups? 20
A. What are the pathways to self-help/support groups? 20
B. How are self-help/support groups promoted? 21
C. Is gender an issue with participants' experiences with groups? 21
D. How is the operation and/or content of self helps/support groups affected by gender? 22

6.2 What is the relationship between gender, self-help/support group participation and utilization of the health care system? 23
A. Is utilization different by gender? 23
B. Is participation in self-help/support groups influenced by the type of disease or condition? 23
C. How do professionals experience participants from self-help/support groups? 23
D. What are the policy (or health services) implications if participants in self-help/support group have different utilization patterns based on gender? 23

6.3 How does gender influence the efficacy of self-help support groups? 24
A. What are gender and diversity sensitive appropriate measures for groups? 24
B. Were gender-specific obstacles considered and addressed? 24

7.0 CONCLUSION 26

ANNOTATED BIBLIOGRAPHY 28

PREFACE

This project, *Uncovering Sex and Gender Differences in Use Patterns of Self-Help/Support Groups: Annotated Bibliography and Research Agenda*, has been guided by a core group:

- **Mebrat Beyene**, Executive Director, Self-Help Resource Association of BC, Vancouver
- **Madeline Boscoe**, Executive Director, Canadian Women's Health Network, Winnipeg
- **Margaret Haworth-Brockman**, Executive Director, Prairie Women's Health Centre of Excellence, Winnipeg
- **Natalie Mulaire**, Chief Operating Officer, Society of Manitobans with Disabilities Self-Help Clearinghouse, Winnipeg
- **Roya Rabbani**, Executive Director, Self-Help Resource Centre, Toronto

Working via teleconferences, this group set the scope for a review of the literature. They commented on an early draft of a discussion paper and annotated literature review, as well as this report. Their feedback has been meticulous and invaluable.

The discussion paper and annotated bibliography were the foundation for an on-line internet workshop in real time using technology from the Community Outreach Group (Learnlinc) in Regina, Saskatchewan. Despite numerous technical challenges 12 people from across Canada participated in a facilitated text-based discussion on November 8, 2005. They provided valuable insights about the area of self-help/support group research, and gave feedback on the discussion document. Participants were:

Linda Bayers, Director, The Self Help Connection, Dartmouth, Nova Scotia

Mebrat Beyene, Executive Director, Self-Help Resource Association of BC, Vancouver, British Columbia

Madeline Boscoe, Executive Director, Canadian Women's Health Network, Winnipeg, Manitoba

Kaysi Eastlick Kushner, Assistant Professor, Faculty of Nursing, University of Alberta, Edmonton, Alberta

Benjamin Gottlieb, Professor, Department of Psychology, University of Guelph, Guelph, Ontario

Margaret Haworth-Brockman, Executive Director, Prairie Women's Health Centre of Excellence, Winnipeg, Manitoba

Natalie Mulaire, Chief Operating Officer, Society for Manitobans with Disabilities Self-Help Clearinghouse. Winnipeg, Manitoba

Laura O'Grady, PhD candidate, University of Toronto, Toronto, Ontario

John Oliffe, Assistant Professor, School of Nursing, University of British Columbia, Vancouver, British Columbia

Ken Orban, Coordinator, Program Services, Canadian Cancer Society - Saskatchewan Division, Regina, Saskatchewan

Natalie Parry, Manager, Cancer Control Programs, National Office, Canadian Cancer Society, Toronto, Ontario

Sari Tudiver, Senior Policy Analyst, Bureau of Women's Health and Gender Analysis, Health Canada, Ottawa, Ontario

Funding for this project was provided by the Institute for Gender and Health of the Canadian Institutes of Health Research.

We hope that the resulting research agenda will stimulate a multitude of both research and sex and gender analysis in the areas of self help groups, support groups and peer support groups.

Robin Barnett,
Vancouver, British Columbia

1.0 INTRODUCTION

Self-help and support groups have gained in popularity since the 1970s. Self-help/support groups provide a component of social support, one of the determinants of health. These groups have been popular forms for health promotion, education, action and empowerment of "patients". Self-help/support groups span the continuum of health services from acute to rehabilitation. They can provide complementary support to professional interventions across the life span, and are consistent with the Institute for Gender and Health (IGH) priority for promoting health in the context of chronic conditions and disabilities. They are also used to promote positive health behaviours through self-care/prevention including in the IGH priority area of addictions. Health Canada's Natural Health Products Directorate links health promotion (including self-help groups) with its definition of complementary and alternative therapies.

The Prairie Women's Health Centre of Excellence (PWHCE) and the Canadian Women's Health Network (CWHN) are two parts of the Women's Health Contribution Program, supported through the Bureau of Women's Health and Gender Analysis of Health Canada. Social support as an influence and determinant of women's health has been part of the work supported by PWHCE. PWHCE has commissioned or been involved in policy-oriented, and community-based research and analysis about social support in relation to Aboriginal women, lesbians, older women and women living in rural communities. CWHN is a national voluntary organization working to improve the health and lives of girls and women in Canada and the world by collecting, producing, distributing and sharing knowledge, ideas, education, information, resources, strategies and inspirations. CWHN provides easy access to reliable health information, resources and research, and communicates the research findings and policy recommendations of the Centres of Excellence for Women's Health and Working Groups in timely and innovative ways. PWHCE and CWHN collaborated on the development and conduct of this project.

Self-help/support groups are rapidly becoming essential components of care given the funding demands upon health care services. Self-help/support groups are not a substitute for health care services. They are one means to produce positive health outcomes. They need to be reinforced and nurtured by other necessary services, and require collaboration with those services.

Research about self-help/support groups is important for an ageing Canadian population facing reduced health care services. A growing national health promotion discourse mirrors demands of Canadians to be more involved in decision-making in health care services and their becoming "empowered" in their own health care. Especially in rural areas, and in cases of rare and chronic diseases, people are using self-help/support groups to take control and responsibility for their own health. Participants and practitioners alike believe that self-help/support groups are an outstanding way of providing care.

Research shows that participation in self-help/support groups can improve health.[1] Randomized clinical studies in the 1980's about metastasized breast cancer showed higher rates of cancer survival for group members.[2] Dr. Dean Ornish's program for treating heart disease makes extensive use of self-help groups. He wrote:

> *"At first I viewed our support groups simply as a way to stay on other aspects of the program I considered more important such as diet, exercise and stress management. Over time I began to realize that group support was itself one of the most powerful interventions."*[3]

Studies have also identified wider societal benefits such as:

- Creating, strengthening and developing community
- Initiating improvements in the medical, social service and education systems
- Reducing health care costs[4]

Understanding why health promotion interventions and health behaviours such as participation in self-help/support groups are, or are not, effective also requires consideration of sex and gender differences – the socially constructed roles and relationships, attitudes, meanings and relative power ascribed to men and women in society[5] – because men and women enact these activities differently. We know that women and men differ in health status

[1] Kyrouz, et. al. 2002. A Review of Research on the Effectiveness of Self-Help Mutual Aid Groups. *The Self-Help Sourcebook: Your Guide to Community and Online Support Groups* by Barbara J. White and Edward J. Madara. New Jersey: American Self-Help Group Clearinghouse. Chapter 5.
[2] Baseley, Nigel, CEO, SMD Self-Help Clearinghouse. May 12, 2003. *The Effectiveness of Self-Help/Mutual Support Groups* (summary notes).
[3] Banks, Eric. 2000. Self-Help and the New Health Agenda. *Self-Help 2000: The Newsletter of the National Self Help Clearinghouse*. Summer issue.
[4] Baseley, Nigel, op.cit.
[5] Tudiver, Sari. 2002. Gender Matters: Evaluating the Effectiveness of Health Promotion. *Health Policy Research Bulletin*. 11(3):22-23.

and patterns of disease, and in their use of the health care system. Understanding why these differences occur (i.e. how sex and gender are determinants of health), and how to improve health outcomes has led to a range of research and evaluation initiatives.

However, research about sex and gender differences in the utilization and value of self-help/support groups is inadequate. The literature is predominantly sex and gender neutral, limiting the effective uptake of knowledge by practitioners and participants in these groups.

The intent of this report is to provide a better understanding of the roles and values of self-help/support groups by examining their issues more particularly through sex and gender analysis. It foresees how the sharing of research and best practices can promote more specific programming with clear sex and gender outcome measures which contribute to the improvement of health status and the health care system. Gender analysis will also help to improve access to self-help/support groups by many diverse communities.

1.1 CONTENTS OF THIS REPORT

- Definitions of self-help/support groups and sex and gender
- Description of the literature search and review of materials
- Data from Canadian and U.S. national surveys
- An overview of findings
- Research agenda
- Annotated bibliography

2.0 DEFINITIONS

2.1 DEFINITION OF SELF-HELP/SUPPORT GROUP

There are numerous definitions of self-help/support groups as well as a wide spectrum of types of groups that define themselves as self-help/support groups. However, there is no clear definition. Some commonalities among the definitions from three Canadian self-help clearinghouses (Self-Help Resource Centre in Toronto, SMD Self-Help Clearinghouse in Winnipeg, and the Self-Help Resource Association of B.C. in Vancouver) are:

- Voluntary
- No fee
- Run by participants
- Based upon shared issues and/or experiences
- Sometimes non-hierarchical
- Self help and peer support are linked
- Empowering
- Meaningful participation
- Education and information
- Emotional support
- Practical support
- Advocacy (individual self-advocates and group collective advocacy)

The focus above is on groups where the participants all share some problem or condition and run the group on their own. There are also groups led by a health professional(s) or co-led by professionals and a participant. These groups share many of the commonalities described above. Some practitioners and researchers believe that these more aptly-termed support groups are distinct from the participant-led community based self-help groups, especially in the case of group participation mandated by courts (e.g. anger management groups or male perpetrators sent to "john schools") or treatments centres (e.g. cancer or alcohol support groups).

There are also groups and activities which are not labeled as self-help/support groups which still share many of the elements listed above. For example, immigrant and refugee groups may identify

their activities as social interaction or social engagement, yet are effectively involved in self-help/peer support. These groups are among those which may be marginal to mainstream self-help/support groups, but who could benefit greatly from links.

No specific definition of self-help/support group is used in this report. Rather, the term is conceived of broadly, to encompass the many different types of groups which can be classified as self-help, support, or mutual aid. These include those run without professional assistance, peer-led support groups, emotional support groups, self-care interventions, groups facilitated by health professionals, online groups for support and discussion, empowerment groups, sport/physical activity groups and skills based groups like parenting groups. Not being limited to a definition enabled access to a wider range of articles and information and therefore, more knowledge about the intersection of sex and gender with self-help/support groups.

The need for research or mapping to develop a proper lexicon on self-help/support groups with or without attention to gender analysis was noted by workshop participants. More precise terminology would provide a way to understand more about who does and does not participate in self-help groups, peer support processes or support groups. There are also multilayered questions about appropriateness of services, offloading of information and support services to fill gaps in care, and who is privileged to be able to volunteer to facilitate/lead groups.

2.2 SEX AND GENDER

Sex is about biology and the difference between men and women, as well as people who are born intersexed (persons with aspects of both male and female), and those who change sex through medical interventions (transsexuals). Biology is influenced by environmental, social, economic and cultural factors which are understood as gender. Gender usually refers to the differences that are socially defined, that are created by cultural norms. These differences are not fixed; they vary between cultures and change over time and may highlight inequalities in the way societies are structured. Gender is an analytic tool for understanding social conditions and processes. Sex and gender also interact.

Social constructions of gender determine attitudes about what men and women are capable of, how they should behave, what kinds of role models and images are presented for women and men, and who will occupy positions of power. Gender affects almost all aspects of women's and men's lives, their needs, opportunities and access to resources.[6] Social constructions also influence perceptions and roles of transgendered people.

People do not always conform to socially defined gender roles. For example, some women may adopt characteristics or behaviour which more closely resemble the socially defined gender role of men. They are born biologically female and perceive themselves (identify) as women, but do not conform to traditional social roles of women (i.e. more masculine than feminine).

Sexuality is a variable linked with both sex and gender which includes heterosexual, homosexual (gay), lesbian, two-spirit and bi-sexual people. There is also gender diversity within these groups. For example, women who are lesbian may identify with terms such as lesbian, lipstick lesbian, queer, butch or dyke.[7] For this report, gender is understood as complex and diverse and not just male and female.

It is the diversity within gender roles and social constructions which underlie the need for both a sex and gender analysis. If one only researches the differences between men and women (sex), we miss valuable information about social context and construction, cultures, power relations and how different peoples express themselves. These differences and their comparison provide ways to understand health outcomes and the effectiveness of measures like self-help/support groups for specific groups and individuals.

[6] B. Hedman et al. *Engendering Statistics: A Tool for Change,* Stockholm: Statistics Sweden, 1996, p 13.
[7] Vancouver/Richmond Health Board. 2001. *Framework for Women-Centred Health*.

3.0 SEARCH

The search of academic literature was limited to English-language articles published after 1995 (with a few exceptions). This review attempted to be inclusive of the diversity of the population in Canada. However, very few articles were found which allow us to do that. Links between self-help/support groups with health in its broadest sense were also considered.

The terms most useful as search words were *self-help* or *support groups* linked with *sex*, *sexuality and/or gender differences*. While other terms like *social support* could be linked with *gender differences*, there is too much literature to review with too little reward by relying on chance. Self-help/support groups is a small subset of the social support area.

Search indices (databases) include: CINAHL, Medline, Psychinfo, Pubmed, Sociological Abstracts, Social service abstracts. Searches were also performed on websites for Health Canada, Canadian Health Network and the Canadian Women's Health Network.

Articles include the following conditions, populations, and types of groups:
Adolescents
Alcohol and drug use
Bereavement
Cancer
Cardiovascular disease
Caregiving
Chronic obstructive pulmonary disease
College students
Divorce and separation
Mental health
On line support groups
Parenting
Lesbian, gay (HIV) and transgender (LGBT)
Telephone support groups
Urology
Women's health movement

Requests for grey literature were posted on list serves:
SLFHLP-L@LISTSERV. UTORONTO.CA
CLICK4 HP
SDOH
CWHN CDN-Women.
Websites: PWHCE.CA and CWHN.CA

4.0 NATIONAL SURVEYS

4.1 CANADIAN SURVEY DATA

The *National Population Health Survey* (1996-97)[8] contained a question: "**In the Past 12 months, did you attend a meeting of a self help group such as AA or a cancer support group?".** Two percent (2%) of Canadians age 12 and older answered yes. According to Statistics Canada there were no real differences between the sexes or among education groups making use of self-help groups. However, 5% of single parents attended self-help groups compared with 4% of individuals in a couple with no children, 3% of unattached individuals, and just 2% of individuals in a couple with children.[9] The analysis about parents and couples is not sex disaggregated. We do know that most single parents are women.

For this project, data were extracted from the *Canadian Community Health Survey* (CCHS) cycle 2.1 from 2003[10] which asked the same question: "**In the Past 12 months, did you attend a meeting of a self help group such as AA or a cancer support group?"** Three percent (3.0%) of females and 2.1% of males said yes. This can be compared to the 1996/97 data and shows an increase in participation for women. The difference in participation between females and males is statistically significant.

Data were also extracted from the CCHS Cycle 1.2[11] from 2002 on Mental Health and Well-Being. The question for Canadians aged 15 and older was "**Not counting internet support groups, did you ever go to a self-help group for help with your emotions, mental health or use of alcohol or drugs?**" indicating lifetime use. Statisticians extrapolate the data to predict that 4.56% of Canadians (age 12 and older) had attended groups (territories not included).

---

[8] This survey did not include First Nations and Inuit peoples. Reserves did not participate and the territories are not included.
[9] Statistics Canada. 1999. *Statistical Report on the Health of Canadians.* Chapter 35.
[10] Reserves and Territories not included. Thanks to Lissa Donner for extracting the 2002 and 2003 data.
[11] Reserves and Territories not included

Women's attendance was 5.36% and men's was 3.73%. Women in British Columbia had the highest attendance at 8.42% compared with 4.76% for men. The lowest attendance rates were in Newfoundland and Labrador with 2.09% for women and 1.26% for men.

4.2 U.S. SURVEY DATA

Several U.S. studies provide some useful information even though they do not include gender analysis. For instance Kessler, et.al (1997) found that large proportions of those who participate in self-help groups for substance use and emotional problems also seek out professional help for their concerns. Some studies have found high utilization of the health care system among people who use complementary and alternative therapies (women utilize them more than men do). Other studies suggest that support group attendance is a predictor of the use of complementary and alternative health care.[12]

Davison, et. al (2000) measured 20 disease categories to determine whether seeking support group help is related to the type of disease. The authors' psychosocial finding is that face-to-face support seeking was highest for diseases viewed as stigmatizing (e.g. AIDS, alcoholism, breast and prostate cancer, anorexia nervosa) and was lowest for less embarrassing, but equally devastating disorders, such as heart disease, migraine, ulcer and chronic pain. The authors suggest that embarrassment and thereby alienation from one's usual support network may be precisely the kind of social anxiety that increases the value of mutual support groups. Attendance in online groups was highest for multiple sclerosis (MS), diabetes, depression, chronic fatigue syndrome, anorexia nervosa, and breast cancer. The lowest rates are for chronic pain, ulcer, migraine, hypertension, and emphysema. The on-line domain may be particularly useful in bringing together those who suffer from rare and debilitating conditions, for which getting together physically presents barriers.

It would have been interesting if Davison et. al had also reflected upon which diseases were more prevalent in and or unique to

[12] Barnett, Robin. 2004. *A Preliminary Framework for Understanding Women's Use of Natural Health Products (NHP) and Complementary and Alternative Health Care (CAHC).* Health Canada: Natural Health Products Directorate, Health Products and Food Branch, and Women's Health Bureau, Health Policy and Communications Branch.

women, men or gay men. For example, among diseases more prevalent in women are anorexia nervosa and bulimia, arthritis, osteoarthritis and rheumatoid arthritis, lupus, fibromyalgia, breast cancer, diabetes, gall stones, gastritis, intestinal cystitis, MS, migraine headaches, anxiety, depression, panic disorders, phobias, and stress.[13] The relationship between efficacy of self-help/support and sex prevalent diseases may shed some light on some of the objectives of self-help such as taking control of one's life and self-determination as well as why self-help groups are so popular in mental health.[14]

[13] Greaves, Lorraine, et. al. 1999. *CIHR 2000: Sex and Gender and Women's Health*. British Columbia Centre of Excellence for Women's Health.
[14] Mulaire, Natalie. August 10, 2005. email comment.

5.0 OVERVIEW OF COMMON FINDINGS

Though in general researchers do not apply gender analysis, there is some discussion of sex differences. A few articles provide a refined, detailed comparison of male and female genders. Articles about mixed lesbian, gay, bisexual and transgendered (LGBT) never make comparisons with heterosexual or mixed groups. And as mentioned previously, the articles do not reflect the diversity of the population of Canada.

There are many unforeseen understandings about self-help/support groups though many of the articles reviewed caution about generalizing from their results, usually for small sample size or specific area of concern. Most findings are contained in more than one study. Generally the literature tells us the following:

- women have higher attendance in support groups
- face-to-face and on line groups attract genders differently
- face-to-face groups are under-attended by persons with low socio-economic status and from diverse backgrounds
- sometimes groups for specific populations exist "side-by-side" i.e. parenting support group for South Asian women and also one for lesbians
- men's involvement may be a reflection of men's changing roles in society
- gay and transgender groups have similar approaches to women's (and lesbian) groups
- knowledge about differing communication patterns between women and men can be applied to understand both participation in and the structures of self-help/support groups.

As Wally Seeley, the Director of the Canadian Prostate Cancer Network states:

> "*Men and women are just different…women who have cancer want to know all the medical details, but they*

also want to reach out and seem more willing to discuss their situation within a group."

Despite the usual and expected anger and fear after being diagnosed (with prostate cancer) many men will clam up as they aspire to ingrained societal expectations of the impervious husband, father and man.[15]

More specific findings from the literature follow. Citations in the following sections refer to the numbered articles in the annotated bibliography (pp 25-51).

5.1 FACE TO FACE SELF-HELP/SUPPORT GROUPS

A. Groups for men

Men are reluctant to seek help and less likely to join a support group. (14, 51) One reason might be linked to men's incomes which are often greater than women's. Men therefore have more access to other kinds of help and support. (18) Another reason might be male socialization. One study found that adolescent boys shy away from peer support to conform to a "macho" image. (8)

Also, male attendance at groups may be less because groups are too female oriented. (3, 25) Rather, numerous articles stated that males prefer "informational" and educational components. (2, 4, 7, 13, 23, 38) Men like to keep up with scientific and medical research (4, 7, 13) and they prefer guidance from leaders, rather than peers, as men appear to favour larger meetings, expert speakers and efficient organizations. (13, 37) Men also use problem-focused coping strategies. (1, 12, 38) For example, more boys attend peer support when it is integrated into curriculum or when it includes a computer or technical component. (8) Some studies point out that men experience emotional benefits despite intentions. (13, 37)

In terms of broad support, it is interesting that men assign high importance to talking with one's spouse or partner. (2, 13, 36, 37, 39) Also, men perceive themselves needing care. (13, 39)

---

[15] Paul Irish. 2004. "Support groups open up strong and silent types: They're helping thousands of men. Patients learn how to discuss disease." *The Toronto Star*. September 7, 2004.

B. Groups for gay men

Support groups for gay men are often described in terms of emotional support, sharing feelings, and coping skills. (11, 41, 45, 56) However, it appears that some gay men are uncomfortable with this approach, and that they prefer information and education. (41)

As in women's groups, storytelling about people's lives is used in groups (45, 56). Such emotional work is seen as mutually sustaining with identity work within a community context. (29, 45,56) Some gay men prefer peer knowledge to professional knowledge about HIV/AIDS. And gay men who have lots of support and friends may not participate in groups. (41)

C. Groups for women

Women in self-help support groups use intimacy and confidence, and informal befriending approaches. (2, 13, 17, 18, 23, 51) Women are interested in emotional impact; (4, 13, 36, 37, 52) they use story telling approaches. (4, 39) And, they also emphasize peer knowledge and smaller group discussions. (13, 17, 32, 37, 38)

Women begin to have contact with group members outside sessions much earlier than men. (5) And women use a wider network of confidants/more supportive relationships than men. (36)

Women continue their caregiving roles while attending support groups. (13, 39) One researcher thinks that societal norms that lead to greater caregiving by women may also result in their greater participation in self-help/support groups. (38)

Some research indicates that groups with women in the minority may not provide room for women's issues, and that special women's groups need to be established. (10, 13) Indeed, there are women who report that they feel more comfortable, and gain more benefits from women's specific peer support groups for mental health issues. (32)

Women's self-help/support groups can also be tools for social change and advocacy. (4)

One interesting finding is that women have better treatment outcomes in alcohol and drug groups. (50)

D. Groups for lesbians

Groups for lesbians share many of the characteristics of groups for women. Some unique aspects in the literature include the fact that

self-help/support groups may provide a social venue for women to meet other lesbians for the purpose of dating (an alternative to bars and sports). (15, 43) Politics (experiences as lesbians in a sexist, heterosexist society) is part of the discourse in groups. (15, 43) According to one study, lesians who attend lesbian AA groups may also attend mainstream AA at the same time. (15)

E. Transgender groups

Transgender groups also use emotional work within a context of identity work as well as storytelling approaches. (44) Researchers found a need for separate groups for specific individuals e.g. female to male, male to female transgendered as well as male cross-dressers. (44) And groups can also be a means for social/societal change to secure rights for transgendered people. (44)

F. Queer groups (mixed lesbian, gay, bisexual and transgendered or LGBT)

Like many group processes, these groups may marginalize those in the minority. (10, 30) Researchers found that asserting commonality needs to be balanced with affirming diversity. (30)

G. Mixed groups of men and women or gay and heterosexual

Researchers suggest that some sessions need to include breakout sessions by gender (33), and that collective work may facilitate respect for different lifestyles. (39) One researcher suggests that more than one man should be included in mixed groups, otherwise the lone man may discontinue participation. (5)

5.2 INTERNET SUPPORT GROUPS

There is a perceived lack of ethnicity among participants in internet support groups. (19) And, although most problem drinkers are male, there are more women in on line support groups. (22) Researchers find gender differences in emotional tone or types of messages. (19, 35, 55) In female-only groups, participants share stories and personal experience and seek emotional support. (19, 22, 24, 35, 42) Male groups seek information and resources. (19, 24) African American women may use the support component less than Caucasian women in an educational/support program. (24)

On-line support groups are one means to increase participation by men because of anonymity - they can avoid face to face situations which may be uncomfortable for them. (24) It is interesting that attendees may not be socio-economically privileged (42) and that meeting outside of internet use is common, possibly more so among women. (42)

In mixed groups, men may take on more female styles of communication i.e. use of disclosure and sharing experiential knowledge. (22, 35, 40, 55) Mixed groups may also favour a more feminine style. (22, 55) One researcher points out that women have changed meanings of male created/defined emoticons to include emotional expression. (55)

6.0 RESEARCH AGENDA

Self-help/support groups are an essential component of care in the Canadian health care system. Groups are frequently provided through the voluntary sector, though primary care and ambulatory services are also increasingly providing programs as the benefits of mutual aid, education and emotional support are recognized. Self-help/support programs can be provided by health or social service professionals (either paid or unpaid) as well as by trained paid or unpaid volunteers. Community based self-help/support organizations are concerned with growing utilization: how to promote and enhance the use of self-help/support groups and with efficacy. Research about self-help/support groups is important for an ageing Canadian population facing reduced health care services.

While individual researchers and research groups will determine their own methodologies in future projects, the participants in this project (November 8, 2005 online internet workshop) emphasized the importance of grounding research in communities and work with communities, in addition to supporting the value and advantages of self-help. This raises a number of tactical questions:

- Are the needs of communities similar to those of researchers?
- Some researchers perceive a “disconnect between biomedical and community services”.
- How can research emanate from communities when funding comes more easily through institutions and universities?
- How can community–based organizations draw in academic expertise and access funds?
- Do self-help/support groups think of gender?

The research that exists tends to discuss the experiences of a fairly educated, white population. Working with diverse communities is one way to ensure the inclusion of research partners and participants more reflective of the Canadian demographic.

Workshop participants also noted the need for both quantitative and qualitative research methods.

Three major research questions were developed by this project:

1. **What are the connections between gender and self-help/support groups?**
2. **What is the relationship between gender, self-help/support group participation and utilization of the health care system?**
3. **How does gender influence the efficacy of self-help/support groups?**

While selecting these three questions, workshop participants indicated that they are not set in any priority listing or considered the only possible questions. These questions set a foundation for future research, and if incorporated by researchers, they have the potential to be of immense use to other researchers, policy makers, health care system administrators, and practitioners to improve health outcomes, ensure greater effectiveness and efficient use of resources. Researchers and evaluators can use these questions as a template to facilitate uptake of gender analysis into research and evaluation.

6.1 WHAT ARE THE CONNECTIONS BETWEEN GENDER AND SELF-HELP/SUPPORT GROUPS?

A. What are the pathways to self-help/support groups?

What are entry points into self-help/support groups? Are there gender differences in how or why individuals are attracted to or engage in self-help groups? Do some women or men have broader networks which bring them to these groups? Do women participate in self-help groups more than men because women under stress might be prone to "tend and befriend"? What about the impact of social determinants like income, culture, rural, and sexual orientation? Do lesbians (and others) use groups to make friends and meet dates?

What part does women's role as caregiver play in male attendance at groups? One news article quotes "The ladies are very important to the group," says (Jack) Garland. "It's often the females who push and urge their husbands along for tests and examinations. When

we're handing out leaflets it's wives, daughters and grand-daughters who seem to stop for a quick chat."[16]

Are organized programs like Reach for Recovery (one to one visitation after breast cancer surgery) better at recruiting women to groups? Or would anyone benefit?

B. How are self-help/support groups promoted?

Are descriptions of self-help/support groups inclusive? In many descriptions of self-help/support groups, statements about emotional support and or disclosure are primary or precede statements about information, therefore possibly making them more attractive to females and LGBT people. Descriptions also may emphasize equality or reciprocity with professionals, possibly making them less appealing to heterosexual men.

What is the role of health care professionals in promoting self-help/support groups?

Membership recruitment can be an ongoing concern. Could more gender specific promotion be related to greater retention of participants in groups?

C. Is gender an issue with participants' experiences with groups?

What are the trajectories of being involved in groups? Do participants drop out, but maybe try again? Who does not get to self-help/support groups? Where do participants go when they leave self-help/support groups?

What gender knowledge and experience contributes to the sustainability and survival of groups? Does the development phase of groups or the historical context affect a gender analysis?

When or why do some groups include policy changes, activism, and advocacy in their discussions and actions? Are sex and gender contributing factors to this occurring or not occurring? Do men's organizational preferences lend themselves to advocacy activities better than women's relationship building? Do LGBT, poverty, or breast cancer groups link with activism because of historical

[16] Paul Irsh, 2004. op. cit.

marginalization by society? How do changing historical conditions and events shape the potential for mobilization of individual participants? What are their subjective experiences?

D. How is the operation and/or content of self-help/support groups affected by gender?

How do self-help support group formats, structures and programming function differently (or the same) for men, women, lesbian, gay and transgendered people from varied circumstances? Are there differences based on the key goals of the group i.e. information focused, mutual aid and support, community action?

Much of the research is about educated white people. Besides gender, what is a function of age, and other demographics such as geographic location, literacy, culture, faith, and income? Are there types of groups or programming which function as self-help/support groups in different communities, but are not identified as self-help/support groups? Would more culturally diverse heterosexual male participants pay greater attention to psychosocial support?

What do different people need when they get to a group? How does any particular group react to different types of new members? How is gender performed, expressed or resisted in groups?

Can women and mixed groups benefit from male type problem focused interventions? Initiatives like the Women's Cardiovascular Health Initiative from Sunnybrook and Women's Hospital in Toronto integrate the idea of women supporting each other with a program of exercise and nutrition that helps women prevent (or recover from) heart disease. Another program that focuses on the power of "doing" is dragon boat teams. Groups of women with breast cancer from all over the world compete. Many of the women involved say it's not a support group - it's about action, notes Terry Mitchell, Psychological Researcher at the Canadian Breast Cancer Foundation Community Research Initiative. [17]

[17] Women's Health Matters. 2002. *Making Connections - Women's Health Support Groups* accessed via the Canadian Health Network website.

6.2 WHAT IS THE RELATIONSHIP BETWEEN GENDER, SELF-HELP/SUPPORT GROUP PARTICIPATION AND UTILIZATION OF THE HEALTH CARE SYSTEM?

A. Is utilization different by gender?

Are participants multiple users of different parts of the health care system? Do participants use complementary and/or alternative health care?

Do some participants only use self-help/support groups and not work with professionals? Are participants in self-help/support groups more satisfied than non-participants with their care in the health system? What vision do participants have of the health care system?

B. Is participation in self-help/support groups influenced by the type of disease or condition?

Studies need to examine if particular diseases which are more prevalent or unique to either women or men correlate with participation in and type of groups. Are there national patterns and prevalence rates for self help/support group membership by condition/diseases? Do professionals in specific specialties or health services refer more patients to self-help/support groups?

C. How do professionals experience participants from self-help/support groups?

Does it differ by gender?

D. What are the policy (or health services) implications if participants in self-help/support groups have different utilization patterns based on gender?

6.3 HOW DOES GENDER INFLUENCE THE EFFICACY OF SELF-HELP/SUPPORT GROUPS?

A. What are gender and diversity sensitive appropriate measures for groups?

What benefits different people? Do we know, for instance, what types of seniors and their concerns or problems are most helped by groups, given that there are more than men? Who benefits from face to face groups and who benefits from online peer support?

What is the relationship between empowerment and participation? Does gender influence how empowerment is perceived? Is empowerment correlated with activism?

B. Were gender-specific obstacles considered and addressed?

Many traditional smoking cessation methods have for the most part, failed to address the factors in women's lives that lead them to smoke and keep them hooked once they have started. For this reason, many women have not had the opportunity to explore their personal concerns and to express their fears and struggles around quitting.[18]

Is knowledge about the social, economic and cultural context of different people's lives applied? For example, the literature review for this project found that AA is popular with women, and that they sometimes have better outcomes than men because of their AA attendance. An exchange on the self-help listserv questioned this type of finding:

> *Drug Court in Los Angeles (a diversion program that uses a 12-Step model) reports a 70 percent success rate with men, but only a 30 percent success rate with women. It is possible that these stats are the result of the sample bias as most of the women in the program have been abused. Abused women often have difficulty with the "powerlessness" concept being a step to recovery, when their past experience of powerlessness as an abused person is so negative. The same people have difficulty with "turning their life and their will" over to a higher power, as these women have histories of turning their lives over to their abusers.*[19]

[18] Deborah Holmberg-Schwartz. 1990. *Catching Our Breath: A Guide for Facilitators*. Winnipeg: Women's Health Clinic.
[19] Ruth Hollman, July 24, 2004 on SLFHLP-L@LISTSERV.UTORONTO.CA

This response is more aligned with the philosophy of Women for Sobriety. It raises questions about how social factors and trauma and abuse are incorporated into the evaluation of self-help/support groups, and how different techniques are used in those groups.

7.0 CONCLUSION

Although self-help/support groups and their association with improving access to information, emotional support and, on occasion action, is increasingly an important component of both the mainstream and alternative Canadian health care systems, the research literature is sparse in terms of sex and gender analysis. It is essential to consider sex and gender differences to understand why health promotion interventions and health behaviours such as participation in self-help/support groups are, or are not, effective. Men and women enact these activities differently because of sex and gender – the socially constructed roles and relationships, attitudes, meanings and relative power ascribed to men and women in society.[20]

This is a limitation not only for researchers, but for all stakeholders in the area of self-help/support groups and health promotion. It is program planners, self-help/support group clearinghouses, facilitators, funders, patients, health care professionals and administrators, who benefit from research, and integrate research knowledge into practice and programs. There is an urgent need to address this, and to bring this area of research up to date with current understanding of sex and gender. Participants in this project recommended academic/community partnership models to undertake this work most effectively.

This project developed three major research questions for others to advance research in this area:

1. What are the connections between gender and self-help/support groups?
2. What is the relationship between gender, self-help/support group participation and utilization of the health care system?
3. How does gender influence the efficacy of self-help/support groups?

In addition, it was clear that there needs to be development of a more precise lexicon of definitions of self-help/support groups and consideration of how they relate to sex and gender differences.

---

[20] Tudiver, Sari. 2002. Gender Matters: Evaluating the Effectiveness of Health Promotion. *Health Policy Research Bulletin*. 11(3):22-23.

We hope that this report and research agenda will generate many next steps including some designated research calls, as well as awareness and education about self-help/support groups and the need for sex and gender analysis.

ANNOTATED BIBLIOGRAPHY

For most articles only summaries of sex and gender information are provided. Some demographic data are also included.

(1) Adamsen, L., Rasmussen, J. M. & Pedersen, S. 2001. 'Brothers in arms': How men with cancer experience a sense of comradeship through group intervention which combines physical activity with information relay. ***Journal of Clinical Nursing*****. 10(4):528**
The study investigated a group intervention programme in Denmark through focus group interviews with participants and professionals. There was agreement amongst the men that it was a personal conquest for each of them to join the team. Physical development was the main reason for joining the programme (well-known training facility and professional expertise was crucial). The programme gave them a feeling of responsibility towards the group as well as an obligation to make a meaningful contribution to establishing comradeship. Humour was an important element.
The authors state that men act foremost by using problem-focused coping strategies, which is why male intervention forms should focus on giving the opportunity to regain control and action by targeting male values and a sense of group belonging. This is an orientation different from the type of social life in female self-help groups where the aim is intimacy and confidence as described in the literature.

The authors suggest that further research is needed to demonstrate whether women can profit from a similar intervention and whether the same results can be achieved in groups of mixed genders. (Editor's note: A point not developed within the article. The researchers are women.)

(2) Breau, R.H. and Norman, R.W. 2003. The role of self-help groups in educating and supporting patients with prostate cancer and interstitial cystitis. ***British Journal of Urology*****.92:602-606**

This is a qualitative study in which the authors observed self-help meetings in Halifax. Patients with prostate cancer (PC) appear to use self-help groups primarily as a medium for advocacy and information-sharing about the disease, whereas patients with interstitial cystitis (IC) seem to use self-help groups for social support and coping skills. PC is a male and IC primarily a female disease. Most participants in PC groups are married, well educated and within 5 years of diagnosis. Even though black men have the highest incidence of and mortality from PC, they attend less. Reasons for this have not been studied. Family members probably provide most social support for most men. Of those who did not attend most felt their spouse and urologist were the best source of support and information. 90% of IC patients are female and 94% are white. There is less social acceptance of IC and treatments are not curative. Of those who did not attend groups 20% felt they did not need help and 90% said they had inadequate time to attend meetings. (Editor's note: reasons apparently not mutually exclusive)

(3) Bui, L.L., Last, L., Bradley, H., Law, C.H., Maier, B.A., Smith, A.J. 2002. Interest and participation in support group programs among patients with colorectal cancer. ***Cancer Nursing*****. 25(2):150-7.**

This is a Canadian study (Toronto) of recruits to the Wellspring program which used a structured survey. This study found that gender did not relate to level of interest in support programs. However, actual attendance may be gender related. Comments from men in this study included one who expressed "that the programs were too female oriented." It is possible that presenting gender-sensitive support groups may increase men's participation in CRC support programs**.**

(4) Cameron, Don & Cameron, Emilie. 2005. ***Support Group Topic Development: Final Report*** **submitted to Peer Support Services, Canadian Cancer Society, BC-Yukon. Vancouver.**

Both qualitative and quantitative methods were employed in this project. Surveys were utilized to determine priority topics.
The ten priority topics for discussion in breast cancer support groups are:

1. The emotional impact of cancer
   Women aged less than 55 have more interest in exploring

emotions such as sadness, anger, fear, grief and loss. They are more likely to be open to discussion of depression (Editor's note: depression is not defined) and counseling.
2. Recurrence
   Coping with recurrence and fear or recurrence was rated much higher by breast cancer respondents than any other group, particularly among younger women.
3. Taking charge of your care
4. Decision-making
   Authors refer to advice from Willow Breast Cancer Services (Toronto) for facilitators to take a "story-telling" approach to this and other topics i.e. describe the experience of decision-making rather than list treatment choices.
5. Talking about cancer
6. Coping issues and strategies
7. Long term issue and rebuilding
   Women aged 65 and above are more interested in advocating for cancer research and services, and more keen to address the issue of moving on from the support group.
8. Finding the positive
9. Complementary therapies
10. Sexuality and relationships

Prostate cancer group men are reluctant to attend "support" oriented groups and emphasize the information component of their meetings. Their ten topics are:

1. Decision-making
2. Taking charge of your care
3. New drugs and therapies
4. Side effects and coping strategies
5. Long term issues and rebuilding
6. Finding the positive
7. Emotional impact of cancer
   Both breast cancer and prostate cancer groups rate similar relative importance to various feelings ie. fear or anxiety highest and guilt lowest
8. Talking about cancer
   Men assign high importance to talking about cancer with one's spouse or partner.
9. Sexuality and relationships
   Members aged less than 65 more interested in sexuality.
10. Complementary therapies

Most meetings revolve around an "informational" component. Younger men rate self-image and self-esteem significantly higher and are also less interested in advocating for cancer research and services.

The Living with Cancer support group (75% women) priorities are more aligned with the breast cancer groups.

(5) Caserta, Michael S. and Lund, Dale. A. 1996. Beyond bereavement support group meetings: Exploring outside social contacts among the members. *Death Studies*. 20:537-556.
This study examines the extent to which bereavement support group participants engage in social interaction with fellow group members outside of the meetings. 144 participants in 26 support groups completed self-administered questionnaires. Women began to have outside contacts initially. However 10 months later men had begun to have outside contact. Those with higher incomes were less likely to engage in outside activities with other members. Men reported higher incomes. Men were always the minority in the group which reduced opportunities for outside contact with other men. Later in the study men may have become more comfortable with group members, particularly the women. This study found that those who engaged in outside interaction were often experiencing greater difficulty at that time (more depressed, more lonely, greater stress levels). The authors suggest that whenever men and women are included in the same support group that it is probably best to make sure that there is more than one man. Although one man may eventually feel more comfortable, there is some risk that he will discontinue participation.

(6) Cordova, Matthew J., Giese-Davis, J., Golant, M., Kronnenwetter, C., Chang, V., McFarlin, S., Spiegel, D. 2003. Mood disturbance in community cancer support group: The role of emotional suppression and fighting spirit. *Journal of Psychosomatic Research*. 55(5):461-467.
This was a quantitative study of 121participants in community based cancer support groups in California. Of this heterogeneous sample, 71% were female. No differences were found between men and women in emotional suppression or mood disturbance.

(7) Coreil, Jeannine and Behal, Ravish. 1999. Man to Man Prostate Cancer Support Groups. *Cancer Practice.* 7(3) 122-129.
Participants and facilitators in 38 groups in Florida completed a mail survey. They were typically retired white men in their 60s and 70s from well-educated professional backgrounds. A content analysis of

newsletters shows psychosocial issues received minimal attention in formal presentations, although the group sometimes had breakout sessions for men who wanted psychological support. The vast majority of participants (83%) indicated that they value receiving information and education about prostate cancer the most. A high value is placed on keeping up with scientific research and medical technology. One group had recently changed its name from a "Prostate Cancer Support and Education Group" to "Prostate Cancer Discussion and Education Group".

Seventy-two percent thought that a one-on-one visitation program is needed to reach newly diagnosed men. The authors urge efforts to include underrepresented populations and suggest that greater attention to psychosocial support may be more attractive to a more culturally diverse audience.

(8) Cowie, Helen, Naylor, P., Chauhan, L.T.P., Smith, P.K. 2002. Knowledge, use of and attitudes towards peer support: a 2 year follow-up to the Prince's Trust Survey. ***Journal of Adolescence*****. 25, 453-467.**

This UK qualitative study (structured and semi-structured interviews) of school peer support systems (ages 13-16) documents difficulties in the recruitment and retention of boys as peer supporters because of peer pressure to conform to a "macho" image. Programs shifted away from formal, counselling-based models to a more informal befriending approach. When orienting the program away from emotions and integrated into curriculum, more boys attend. None of the teachers (almost all women) interviewed commented on gender imbalance. Male peer supporters felt confident enough in themselves to challenge stereotypes. Some teachers involved boys in creating websites, using computers and being involved in forms of peer support that concerned mentoring and advice giving. Conclusions include suggesting future investigation of systems successful in recruiting boy peer supporters and male teachers and of sex differences in the development of empathy during the adolescent years.

(9) Davison, Kathryn P., Pennebaker, J.W., Dickerson, S.S. 2000. Who Talks: The Social Psychology of Illness Support Groups. ***American Psychologist*****. 55(2):205-217.**

Support group participation was measured for 20 disease categories in four U.S. metropolitan areas. (Editor's note: No sex or gender analysis was done, especially differentiating those diseases/conditions which are more prevalent or unique to different

sexes) The authors' psychosocial finding is that support-seeking was highest for diseases viewed as stigmatizing (e.g. AIDS, alcoholism, breast and prostate cancer, anorexia nervosa) and was lowest for less embarrassing, but equally devastating disorders, such as heart disease, migraine, ulcer and chronic pain. The authors suggest that embarrassment and thereby alienation from one's usual support network may be precisely the kind of social anxiety that increases the value of mutual support groups.

After adjusting for prevalence, AIDS patients, for instance, are 250 times more likely to participate in a face to face support group than hypertension patients. Breast cancer patients have formed over 40 times as many support groups as heart disease patients.

Attendance in online groups was highest for MS, diabetes, depression, chronic fatigue syndrome, anorexia nervosa, and breast cancer. The lowest rates are for chronic pain, ulcer, migraine, hypertension, and emphysema. The on-line domain may be particularly useful in bringing together those who suffer from rare and debilitating conditions, in which getting together physically presents barriers. The authors also speculate about anonymity and neutralizing of social factors. Support levels in cardiovascular disorders combined are only slightly higher than those for anorexia, a condition whose prevalence is almost 1,000 times less.

(10) Feliz-Ortiz, Maria, Salazar, M. R., Gonzalez, J.R., Sorensen, J.L., Plock, D. 2000. A qualitative evaluation of an assisted self-help group for drug-addicted clients in a structured outpatient treatment setting. *Community Mental Health Journal.* 36(4):339-350.
This is a qualitative evaluation of a semi-structured, client-led support group. Participants are from a public outpatient methadone maintenance treatment program; all middle-aged Whites of low socioeconomic status, mostly men. No women regularly attended the drop-in group. The authors hypothesize that women were "crowded" by the men i.e. they did not have enough opportunity to speak; and that they may not have identified with the men's issues raised in the group or felt uncomfortable raising women's issues in the presence of men, including issues around sex trade, reproductive health and "man" problems. After the first year of the group, a women's assisted self-help group was established.

(11) Fontaine, Kevin, McKenna, L., Cheskin, L. 1997. Support group membership and perceptions of control over health in HIV+ men. *Journal of Clinical Psychology*. 53(3):249-252.
This is a quantitative study using a self-report questionnaire to gather data. "Support groups for HIV+ men attempt to provide emotional, practical and informational support, affording members the opportunity to share feelings, develop coping skills and a forum to consider existential issues." This study compared 155 HIV+ gay/bisexual British men who were or were not members of an AIDS support groups. Those in a support group reported higher frequencies of perceptions that both oneself and powerful others (health professionals) are major determinants of one's health. Support group members also reported a lower frequency of perceptions that chance factors greatly influence one's health.

(12) Frey, Jo Ann. 2000. Gender difference in coping styles and coping effectiveness in chronic obstructive pulmonary disease groups. *Heart & Lung*. 29(5):367-377.
154 surveys in Ohio were analyzed in this quantitative comparative study. Men were enrolled longer in pulmonary rehab programs than women and men were noted to be more active in the programs. No statistically significant gender differences existed for overall coping use or effectiveness. Of clinical significance was women's use of the following coping styles more than men: confrontational, evasive, fatalistic, palliative and supportive. This may mean that women with COPD recognize the problems they encounter and then confront the situation. The authors wonder if this study echoes other research findings that it is not manly to admit to vulnerabilities and to ask for emotional support.

(13) Gray, Ross, Fitch, M., Davis, C., Phillips, C. 1996. Breast cancer and prostate cancer self-help groups: Reflections on differences. *Psycho-oncology*. 5:137-142.
This article makes comparisons between qualitative interview data from two related studies. The authors argue that support needs and appropriate interventions cannot be assumed to be the same for men and women. Men emphasize the importance of information and advocacy and are well served by large meetings, expert speakers and efficient organizations. Women emphasize the importance of intimacy and peer knowledge and are well served by smaller group discussion, a focus on emotional support and friendship, and by less emphasis on business, advocacy and outreach activity.

The authors note that, regardless of their intentions, men often ended up experiencing emotional benefits of discussion of common

concerns with other prostate cancer patients, suggesting that men's primary approach to social support is amenable to change. There were a few women intensely involved in advocacy activities. This may reflect the longer experience of breast cancer groups in struggling to integrate advocacy with support. Prostate groups are new and may yet encounter situations of being split in too many directions. Women were more alert to the costs of advocacy.

One of the most compelling differences between prostate and breast cancer groups relates to the involvement of family. Men spoke about prostate cancer as a "family affair" and spouses participated in meetings in a substantial way. Breast cancer survivors did not typically see their husbands as wanting to be involved with their groups, nor did they think that such involvement was likely to work even if the men were interested. Gender socialization provides a perspective on this. Women are caregivers. Men's socialization leaves them less prepared, and sometimes, less willing, to assume active caregiving roles when a partner becomes ill. Women may see attending prostate cancer groups as part of their caregiving role.

Men made more significant efforts to gain the support of physicians and other stakeholders in the health care system. Women's emphasis tended to be about women owning and controlling their own groups, safe from sometimes disempowering encounters with the health care system and professionals.

Also of interest: breast cancer survivors talked about the value of laughter as well as the need to respond to deaths of members. Men did not mention these things. Men were more concerned about issues of sexuality.

The degree to which these current differences are a function of gender, age of participants, development phase of groups, historical context, and other factors remains to be clarified by future research.

(14) Gray, Ross, Fitch. M., Labrecque, M., Greenberg, M. 2003-2004. Perspectives of prostate cancer support group members on men's health issues and masculinity. *International Journal of Self Help & Self Care*. 2(3):255-268.
This paper is based on 26 qualitative interviews with men after they attended an educational drama *No Big Deal?* which concerns issues facing men with prostate cancer and their spouses. The authors cite numerous studies that show men engage in more behaviours that damage health than do women and fewer behaviours that improve health. The authors argue that conceptions about masculinity are

implicated in this trouble. Experience with prostate cancer support groups extend participant's knowledge about men's coping patterns and provides experiences that challenge, or at least extend, men's usual ways of coping. Chief among problems cited was men's habitual tendency to avoid communicating with family and friends about personal health (and other) matters. Many in the group had learned it can be helpful to be more open about one's experiences. However, the rhetoric of improved communication espoused in support groups may not always be taken seriously, or even necessarily absorbed by individual members.

(15) Hall, Joanne M. 1994. The experiences of lesbians in alcoholics anonymous. *Western Journal of Nursing Research*. 16(5):556-576.
This is a feminist ethnographic study. Other studies found that as lesbian bars find it increasingly difficult to survive financially AA meetings seem to be replacing some of their social functions. Few participants attended lesbian AA meetings exclusively. Most participants also associated with mainstream AA. Some found that interaction with straight people was more easily accomplished in AA than in other environments. Others saw AA as clearly discriminatory and excluding culturally distinct persons. A majority had sought out lesbian AA meetings at some point, suggesting a need for identifying and affirming one's cultural distinction and connecting with one's own community.

Some lesbians believed in the official recovery approach found in AA, while others were more self-directed. Some complained that their daily experiences as women in a sexist, heterosexist society were not considered proper topics for discussion; yet they wanted the support for recovery.

(16) Hildingh, Catherine & Fridlund, Bengt. 2001. Patient participation in peer support groups after a cardiac event. *British Journal of Nursing*. 10(20):1357-1362.
This Swedish quantitative study in a rural area found that there was no difference between attenders and non-attenders regarding age or occupational background except with regard to gender. Almost 3 times as many men as women completed long questionnaires. 54% of women participated in peer support groups and only 24% of men. No statistical differences existed between attenders and non-attenders regarding general health, quality of life, attitude to life and social support. A conclusion which was not gender analyzed was that attenders are somewhat more anxious than non-attenders,

whereas non-attenders have a more relaxed attitude to life and higher self-esteem than attenders.

(17) Humphreys, Keith. 2004. ***Circles of Recovery: Self-Help Organizations for Addictions*****. New York: Cambridge University Press. Pages 47 and 88-93.**
The author describes Al-Anon's shift in gender relations in western countries as husband and wife relationships have changed since the 1950's – from being patient and understanding and not "usurping the husband's role as head of the family" to acknowledgement of a wife's need for personal control, respect and independence.
He also describes Women for Sobriety's (WFS) history beginning in the 1970s which is consistent with the US feminist movement. The creator, Jeane Kirkpatrick designed the organization in direct contrast to male-biased aspects of AA. She considered AA's emphasis on minimizing grandiosity and instilling humility appropriate for arrogant, self-involved men, but damaging to women alcoholics who more commonly suffered from low self-worth and lack of confidence. WFS is concerned with building up rather than minimizing the self. WFS does not use sponsors or encourage lifetime membership to prevent dependence. Members are encouraged to take personal credit for abstinence as a way of building self-confidence. WFS makes no mention of a Higher Power or God. There is no tradition of anonymity and members can go public about recovery. Meetings end with members joining hands and saying. "We are capable and competent, caring and compassionate, always willing to help another, bonded together in overcoming our addictions."

Demographics from a North American survey indicated that members were mostly Caucasian (98%), well educated, and a large proportion of whom (about a third) continue to attend AA as well.

(18) Hsieh, Sumin and Hollister, David.C. 2004. Examining gender differences in adolescent substance abuse behaviour: comparisons and implications for treatment. ***Journal of Child & Adolescent Substance Abuse*****. 13(3):53-70.**
Statistical analyses were performed using 6-month post-treatment follow-up data from over 2000 subjects in the U.S. Females showed better attendance in aftercare or self-help groups. However, the results of parental attendance of ALANON/ALATEEN did not show any difference across gender. More females had psychological difficulties, sexual abuse experience, and family stress before treatment. Males had more school and legal problems and lower involvement in religious activities. The authors speculate that this

difference might be related to sex role socialization. Females are traditionally taught to be more dependent on and involved in the interpersonal environment within the family. Males usually have more exposure to influences outside the family and are more influenced by peers in school or work place. Therefore it was not surprising that females had higher attendance in self-help support group and better treatment outcomes. The authors recommend that male adolescents may generally need more post-treatment services than female counterparts. Post-treatment variables, especially attendance at AA/NA or other self help support groups, were the most powerful discriminator for substance abuse status.

(19) Im, Eun-Ok, Chee, W., Tsai, H-M., Lin, L-C., Cheng, C-Y. 2005. Internet cancer support group: A Feminist analysis. *Cancer Nursing*. 28(1):1-7.
This was a qualitative analysis of issues on Internet cancer support groups (ICSGs). Ethnicity and gender issues identified are: (a) the lack of minority members in ICSGs; (b) a larger number of women-only ICSGs than men-only ICSGs; (c) gender differences in patterns of online participation; (d) difficulty in identifying ethnicity and gender of the participants; and (e) gender differences in emotional tone or type of messages.

Female participants tended to share their stories and seek emotional support. Male participants tended to seek information and resources. The messages posted by persons with female user names tended to be warm and supporting. The messages by persons with male user names tended to be very concise and informative. One noticeable gender difference was that the persons with female user names were more likely to respond to a posted message than the persons with male user names; and the response by the persons with male user names tended to be shorter.

(20) Janowsky, David S., Boone,A., Morter,S., Howe,L. 1999. Personality and alcohol/substance-use disorder patient relapse and attendance at self-help group meetings. *Alcohol and Alcoholism*. 34(3):359-369.
Using various personality tests and following 62 patients, the authors find that attendance at self-help group meetings is not affected by gender, rather by specific personality variables such as being less shy.

(21) Kessler, Ronald C., Mickelson, K.D., Shanyang Zhao. 1997. Patterns and correlates of self-help group membership in the United States. *Social Policy*. 27(3):27.
This study presents data from a U.S. national survey and excludes support groups that involve professionals. Synthetic cohort analysis suggests that group participation has been rising over the past three decades, excepting groups concerned with eating disorders or with life transitions. More than one-third of participants are involved in groups for substance use problems. Large proportions of people who use self-help groups for substance (50%) and emotional (76%) problems also see a professional for these same problems. (Editor's note: In Canada women use the health care system more than men.)

Overall group participants are more likely than non participants with the same problems to be young, female, white and unmarried. Women are more than twice as likely to participate in groups as men, the exception being groups for substance use where there is no significant sex difference in participation. They have lower incomes than non participants, although the opposite is true in groups for eating disorders. Those reporting less support and more conflict in their social networks, those with a lower sense of personal control and higher levels of "neuroticism", were more likely to participate in groups than those with more supportive networks. But participants do not differ from non-participants in other personality dimensions that might be considered important for participating in groups such as extroversion or commitment to a personal growth ideology.

Participants in substance use groups report attending more meetings than those in other self-help groups resulting in 70% of all self-help group visits in the past 12 months. In contrast, groups helping with transitions have low attendance. (e.g. bereavement, disability, parenting)

(22) Klaw, Elena, Huebsch, P.D., Humphreys, K. 2000. Communication patterns in an on-line mutual help group for problem drinkers. *Journal of Community Psychology*. 28(5):535-546.
This was a quantitative analysis of 376 randomly selected messages on an on-line mutual help group. Although most problem drinkers are males, 72% of (Internet) posts for which the author's gender could be identified were written by women. No gender differences were found in communication patterns. Self-disclosure was the most frequently used code (66%). In some cases, self-disclosure functioned as an indirect request for support. In others, it appeared to provide both emotional support and information. The high

prevalence of self-disclosure statements and the large topical variability of the posts suggest the provision of global, nonjudgmental support was more essential to group discussion than was the exchange of specific information and advice (36.7% of all posts).

Since approximately 2/3 of American Internet users are males (1998 statistic), women who belong to on-line groups may be atypical of female help-seekers, and therefore, less likely to use gender specific types of communication. Conversely, self-help groups may actually favour a more feminine style of communication.

(23) Klemm, P., Hurst, M., Dearholt, S.L., Trone, S.R. 1999. Cyber Solace: Gender difference on Internet cancer support groups. ***Computer Nursing*****. 17(2):65-72.**
This study analyzed postings from prostate cancer, breast cancer, and mixed cancers internet support groups. Information giving/seeking was ranked first in the prostate group, and personal experience took priority in the breast group. Men were more than twice as likely to give information and women more than twice as likely to give encouragement and support. Personal experience messages were ranked first in the breast group, second in the prostate group, and fourth in the mixed group. 45 messages from the prostate group had an activist focus not identified in the breast cancer or mixed groups. Topics related to sex and sexuality were almost absent from all lists. Most of the participants in computer support groups that have been studied were Caucasian and had more than 12 years of education.

(24) Klemm, Paula, Bunnell, D., Cullen, M., Soneji, R., Gibbons, P., Holecek, A.2003. Online cancer support groups: A review of the research literature. CIN: ***Computers, Informatics, Nursing*****. 21(3) :136-142**
This was a literature review. Information giving/seeking was a priority for men in a prostate group. In message content for people with prostate, breast, or colorectal cancer, women engaged in supportive responses more frequently than men did. One gender difference in face-to-face cancer support groups was that men were as likely as women to confide in each other about their cancer, but women used a wider network of confidants than men did.

African American women in one study of CHESS used the support component less frequently than Caucasian women did, although the reason for this is unclear.

Heterogeneous samples that include ethnic minorities, different age groups, diverse cancer types, and men are needed. Perhaps on line support groups are one means to increase participation by men because participants are relatively anonymous and can avoid face-to-face situations that may be uncomfortable for them.

(25) Krizek, Claudette, Roberts, C., Ragan, R., Ferrara, J., Lord, B. 1999. Gender and cancer support group participation. *Cancer Practice*. 7(2) 86-92.
This study consisted of qualitative telephone interviews with 130 women with breast cancer and 87 men with prostate cancer. Researchers found that men are less likely to join a support group, but those men who do join attend meetings for about 1 year, as do the women who join. The authors found that support groups are disproportionately under used by certain groups besides men – minority members and persons of low socioeconomic status. Women were also more likely than men to attend at least a single support group meeting. Men and women cite essentially the same reasons for participation: to learn more about their diagnosis, to share their concerns, and to compare their physical and emotional progress with other individuals. Preliminary analysis shows that the most common reason for not attending was that the respondent did not feel a need for support.

Gender differences could be attributed to factors such as the scheduling of meeting in the afternoon which is less accessible for men who are in the workforce. Some support, albeit weak, was lent to the unspoken hypothesis that women come for emotional support and men come for information. But men report no less interest than women in "sharing their concerns" and "comparing their emotional and physical progress" with other patients. The authors suggest marketing support groups differently e.g. "men's information group".

(26) Kyrouz, Eliana M., Humphreys, K. and Loomis, C. 2002. A review of research on the effectiveness of self-help mutual aid groups. *The Self-Help Sourcebook: Your Guide to Community and Online Support Groups* by Barbara J. White and Edward J. Madara. New Jersey: American Self-Help Group Clearinghouse. Chapter 5.
No sex or gender analysis. Some articles cited for male or female groups. Many dated pre 1995.

(27) Luke, Douglas A., Roberts, L, Rappaport, J. 1994. Individual, group context, and individual-group fit predictors of self-help attendance. ***Understanding The Self-Help Organization: Frameworks and Finding,*** **Thomas J. Powell editor. Thousand Oaks, CA: Sage Publications. Chapter 6, pages 88-115.**
This study is part of a large-scale evaluation project of GROW (for persons with serious mental illness or psychiatric hospitalization). 861 different people were observed attending at least one GROW meeting. They ranged in age from 15 to 85, tended to be single (73%), white (97%), female (60%) and have some education beyond high school (60%). Individuals who are older, have more education, and have never been married are more likely to attend for longer periods of time. Persons who are higher functioning are more likely to drop out sooner. Gender had a significant effect on attendance duration. A GROW member is more likely to stay on if the first meetings attended have more men in them. A person is 102% more likely to drop out of GROW in any particular month if the first group attended was completely female. The authors found that women who attend GROW for over a year are those that first attended mixed-gender meetings. Males who attend mostly male meetings are the most successful – over 50% of them attend for at least 5 months. Women respond most negatively to meetings that are mostly female (median survival time is less than 2 months).

The authors note research that individuals (both women and men) in Western society evaluate male characteristics and activities more positively than female characteristics. Another explanation is that men and women form relationships differently and are different in group settings. The group will be easier or harder to enter, depending on the gender mix. For example, a mostly female group might have a complicated relationship system that has been built up over time and hence might be more resistant to new members joining.

(28) McGovern, Margaret. 2001. ***The Use of Mutual Support/Self-Help in the Prevention, Management and Care of Chronic Physical Disease in Older Canadians.*** **Toronto: The Self-Help Resource Centre of Greater Toronto.**
A report commissioned by Health Canada included a literature review, evaluation of best practices, consultations with key informants and proposed recommendations and guidelines for mutual support/peer support strategies. There is no sex or gender analysis.

(29) Martin, David, Riopelle, D., Steckart, J., Geshke, N., Lin, S. 2001. Support group participation, HIV viral load and sexual-risk behavior. *American Journal of Health Behavior*. 25(6):513-527.
This quantitative study used a questionnaire with participants in a Shanti unstructured support group for gay men in Los Angeles. The authors refer to investigators who suggest that community norms are an important determinant of HIV risk behaviour change. They also suggest that experiential groups allow greater opportunity for participants to share their feelings than do more structured educational groups and, therefore, create an atmosphere of greater social support and trust than do more structured cognitive behavioural approaches.

(30) Masequesmay, Gina. 2003. Negotiating multiple identities in a queer Vietnamese support group. *Journal of Homosexuality*. 45(2/3/4):193-215.
Unsatisfied with existing queer (LGBT) support groups, many racial minorities and women splinter off to form their own groups where they believe a focus on gender and/or race will better suit their needs. This participant-observation study with O-Moi, a support group for Vietnamese lesbians, bisexual women and female-to-male transsexuals, suggests that group processes construct a hierarchy that centers and normalizes experiences of bilingual Vietnamese lesbians. This marginalizes bisexual women, transgender men and Vietnamese/English monolingual members because they were in the minority in the group. The author suggests that asserting commonality needs to be balanced with affirming diversity.

(31) Meissen, Greg, Warren, M.L., Kendall, M. 1996. An Assessment of college student willingness to use self-help groups. *Journal of College Student Development*.37(4):448-456.
This article presents data from needs assessment interviews with a random sample of 270 students and 52 selected key informants. Female students had more positive intentions to seek assistance from a self-help group than male students. Women indicated they were significantly more likely than men to attend a group for each of the 16 issues investigated including alcohol abuse, eating disorders, depression, death of a loved one, divorce or separation, child-rearing, childhood abuse, and sexual harassment. Those who had prior experience with self-help groups were more likely to participate in a group in the future.

(32) Morrow, Marina. 2003. *Mainstreaming Women's Mental Health: Building a Canadian Strategy*. Vancouver: British Columbia Centre of Excellence for Women's Health Policy Series.
This is a review or research and best practices leading to recommendations for policymakers. Peer support and self-help have long been recognized as key components of recovery and of maintaining wellness for people with mental illness. Despite this, very few studies have examined the role that peer support and consumer leadership might play specifically for women, or how programs might need to be modified to better meet the needs of women.

Some women report that they feel more comfortable and gain more benefits from women-specific peer support groups, but few such supports are available, especially for women with mental illness who have had experiences of physical or sexual violence.

(33) Murphy, S.A. 1997. A bereavement intervention for parents following the sudden, violent deaths of their 12-28 year-old children: description and applications to clinical practice. *Canadian Journal of Nursing Research. 29(4):51-72.*
This report describes a randomized clinical trial involving parents bereaved by the violent deaths of their 12-28 year-old children. A problem-focused support and emotion-focused support program and control group was followed by researchers. Retention by gender was comparable for both intervention and control groups. Mothers who started out with high levels of distress appeared to benefit more than mothers who started out with lower levels of distress from the support program. Fathers, regardless of initial distress levels, did not appear to benefit from the intervention. Therapeutic Group Factors were measured each week. Five (altruism, catharsis, cohesion, instillation of hope and universality) were rated significantly higher by the mothers than the fathers. The suggestion for future programming is that some sessions need to include breakout sessions by sex.

(34) Ogborne, Alan C. and Dewit, David J. 1999. Lifetime use of professional and community services to help with drinking: Results from a canadian population survey. *Journal of Studies on Alcohol*. 60(6):867
This is an analysis of data from a survey of 12,155 Canadian adults (response rate 75.6%) conducted in 1994. In the table for lifetime use of help for alcohol problems, among lifetime drinkers no women ever went to AA, while 2.4% of men 30-49 did and 1.7% of men

50+ did. Since this survey reported on all help-seeking there is a discussion of how women are more likely than men to interpret symptoms of drinking problems as depression or anxiety and thus seek help for mental health problems. Help-seeking for drinking occurred rather infrequently for both men and women. Studies involving larger numbers of people are needed.

(35) Owen, Jason E., Yarbrough, E.J., Vaga, A., and Tucker,D.C. 2003. Investigation of the effects of gender and preparation on quality of communication in Internet support groups. ***Computers in Human Behavior*****. 19(3):259-275.**
Linguistic Inquiry and Word Count were used to measure levels of emotional and cognitive expression in messages sent to undergraduates enrolled in same-gender support groups to discuss shared experiences of having a loved one with cancer. Males exhibited decreasing use of affective words over time, whereas females used affective words at a level that was consistent over time. Hypothesized gender differences in the content of communication were not observed. However, males and females demonstrated significantly different responses to the group preparation manipulations and distinct patterns of communication over time. Males and females respond differently to suggestions about how to communicate online. Because males also exhibit less cognitive and emotional processing over time when compared to females, efforts to change communication patterns may need to be tailored to address gender specific attitudes. Within same-sex support groups, males may initially respond to prompts and facilitation to share insights and emotions, but subsequent writing behaviour may be more heavily influenced by social reinforcement (or lack thereof) from the group.

(36) Oygard, Lisbet. 2001. Therapeutic factors in divorce support groups. ***Journal of Divorce & Remarriage*****. 36(1/2):141-158.**
This is a quantitative study of participants in 44 divorce support groups from across Norway. Catharsis, universality, and cohesiveness were related to the groups' impact upon adjustment to divorce among females, and catharsis to adjustment among males. The reason for this may be understood in terms of socialization patterns where females are encouraged to be more relationship oriented. When controlling for other variables, new partner was associated with adjustment to divorce among males. This may indicate that within marriage, more husbands use their wives as confidants than vice versa. Women report more supportive relationships than men.

(37) Oygard, Lisbet & Hardeng, Stein. 2001. Divorce support groups – How do group characteristics influence adjustment to divorce? *Social Work with Groups*. 24:69-87.

This study is partly based on a qualitative study of 18 participants in divorce support groups in Norway. Gender differences were observed in that males' adjustment was related to group size and females to the degree of emotional support and guidance from the group. Males attended larger groups significantly more than women. Small differences regarding other variables were observed. Younger women reported better adjustment as a result of group participation than older women. For males, those who had a new partner reported being better adjusted as a result of group participation. For males, guidance from the leader in the form of information was important. For women, guidance from other members was important. Similarities were that both sexes benefited if groups had active leaders, and if they were satisfied with the guidance from the leader.

(38) Pickett-Schenk, Susan A. 2003. Family education and support: Just for women only? *Psychiatric Rehabilitation Journal*. 32(2) 131-139.

This U.S. article reviews studies of education and support programs for families of adults with mental illness and provides preliminary results of ongoing evaluation of the Journey of Hope family education program which is peer-facilitated. Most participants are women. Gender differences in illness course and treatment outcomes may help explain this. Men have an earlier age of onset of schizophrenia with a higher incidence for males under the age of 30 and for females over the age of 40. Men exhibit more physically aggressive and assaulting behaviours. Adult men with mental illness have poorer social networks, are less likely than women to be or to have been married, and are less likely to have lived independently prior to their illness. Families who lived with male adult relatives had greater levels of distress than families who lived with ill female relatives. They report more negative and less satisfying relationships with men. The author suggests that the same societal norms that lead to greater caregiving by women also may result in their greater participation in education programs and support groups. Men tend to enact direct, targeted solutions to problems and try to resolve problems on their own. Women, on the other hand, are more likely to seek solutions and support from others. In the ongoing evaluation female participants reported increases in knowledge of the causes and treatment of mental illness, self-esteem, coping ability, perceived social support as well as increased caregiving satisfaction and improved relationships with ill relatives. Male participants only reported increased knowledge.

The author suggests emphasizing the informational, rather than social focus of programs to increase men's involvement as well as promoting men only groups, advertising in male settings, and sponsoring events in which local sports figures speak. Another suggestion is a daylong educational workshop held as part of a men's weekend fishing retreat.

(39) Rasera, Emerson, Vieira, E.M., Japur, M. 2004. Influence of gender and sexuality on the construction of being HIV positive: as experienced in a support group in Brazil. *Families, Systems & Health*. 22(3):340
This is a qualitative study based on a discursive analysis of group conversations. Four topics were identified: trajectory of infection, initial reaction to the diagnosis, revelation to peers. and relatives and concerns for the future. Men's and women's narrative reports of how they became infected were remarkably different. Heterosexual men who did not use drugs did not report their trajectory, neither did men infected through homosexual sexual practices. Injection users were very straightforward. Women reported clearly and explicitly that they were infected by their significant others.

Despite their different sexual practices, all of the men reported work as a factor in the construction of their initial response to HIV. Women reported domestic interactions as the most important part of their lives affected by HIV. Heterosexual men did talk about family relationships and some talked about supportive families. Many were perceived as in need of care, unable to live by themselves. Women continued in caregiving roles.

In group sessions women spoke more about the future. This association with motherhood allows for active self care. Heterosexual men had a discourse of "waiting" and reconstruction. Drug users linked waiting with fate and prayer resulting in fatalism and resignation. For gay men the future was realistic with a bit of hope.

The authors argue for collective conversation that may facilitate respect for different lifestyles among participants which may contribute to exploration of alternative strategies for facing HIV/AIDS.

(40) Salem, Deborah A., Bogat, G.A., and Reid, C. 1997. Mutual help goes on-line. *Journal of Community Psychology*. 25(2):189-207.
This quantitative/qualitative case study investigated an on-line mutual-help group for persons suffering from depression. Unexpectedly, the group was more highly used by men than women. In addition, the content of men's posts was virtually identical to those of women's. There were gender effects for two variables. Men made more experiential knowledge comments than did women; however, women made more group structure/process comments than did men. Disclosure comments were the most common type of interaction coded, occurring in 51% of the postings. Men were more likely than women to use disclosure as a means of sharing experiential knowledge.

Men may be more comfortable providing and receiving help through on-line communication than through in-person forms of helping and receiving.

(41) Sandstrom, Kent L. 1996. Searching for Information, Understanding, and self-value: The utilization of peer support groups by gay men with HIV/AIDS. *Social Work in Health Care*. 23(4):51-72.
This is a qualitative study of 25 gay men who ranged in age from 20 to 56. About half had post-secondary education. Only two were African American. Most men lived in a large Midwest metropolitan area. 16 of the 25 had participated in support groups. They choose support groups for three forms of support:
(1) Information and advice. Long term participants often stressed how they had learned more through the support group than through consultations with physicians.
(2) Empathy and emotional relief. Support groups served as a source of emotional relief for long term participants struggling with more advanced HIV related symptoms. For example, some described not having to rely as heavily on lovers, friends or family for emotional support. This "normalized" their relationships with others. A few men who had dropped out of support groups stressed that they felt uncomfortable about discussing their feelings in a group context. Some of them thought of support in terms of the exchange of information and coping strategies.
(3) Camaraderie and friendship. Reasons for not participating included having lots of support and friends and being in good health.

(42) Sarkadi, A. and Bremberg, S. 2005. Socially unbiased parenting support on the Internet: a cross-sectional study of users of a large Swedish parenting website. *Child: Care, Health & Development*. 31(1):43-52.
This quantitative study used an anonymous survey posted on a parenting website. Over 2000 users completed the survey. Most respondents (95%) were female (mean age 30.6 years). Their educational level was slightly, but not significantly higher than that in the general population, whereas 68% had income levels at or under the national average, contradicting the intuitive hypothesis that users would be socio-economically privileged. Living without a partner and having lower levels of income and education increased perceived support. The perception that other parents' opinions are more valuable than the advice of experts was influential.
The lack of fathers, however, was a surprising finding in a country such as Sweden with relatively high gender equity and social policies aimed at increasing the father's involvement in child rearing. The male respondents were somewhat older (mean age 34.9 years) compared to 30.3 years for women. A higher number of men had salaries in the highest category, though only 54% of men were full-time workers. Educational levels were similar in both genders. There were more lone parents among the men, not only in this sample, but compared with the general Swedish population. The perception that the opinions of other parents are more valuable than expert advice was not influential for fathers' perceived support.

Overall respondents reported high levels of self-esteem, were frequent users of the website, and many of them had organized to meet with one another.

(43) Saulnier, Christine Flynn. 1994. Twelve steps for everyone? Lesbians in Al-Anon. *Understanding the Self-Help Organization: Frameworks and Findings*, ed. T. J. Powell. Sage Publishers: Thousand Oaks, CA. Pages 247-271.
Al-Anon was originally designed with women in mind. This was an ethnographic research project using a case study of lesbian Al-Anon meetings. Concern was sometimes expressed openly about the place of lesbians in the larger AA/Al-Anon organization. The author observed much political discussion in meetings with the focus on the impact that political forces have on the individual. Sexuality was only occasionally discussed openly, but there was sometimes a dating atmosphere in the meetings and discussion of dating problems was sanctioned. There were also many women who report that alcoholism had not affected their lives directly. The author wonders whether this is indicative of a lack of alternatives for those

who need support as well as the need for belonging – for a place to be acknowledged and accepted as lesbians.

(44) Schrock, Douglas, Holden, D., Reid, L. 2004. Creating emotional resonance: Interpersonal emotion work and motivational framing in a transgender community. *Social Problems*. 51(1):61-81.
This is an observational study of white, middle class transgender support group meetings in a mid-sized southeastern U.S. city, and data from two internet groups. There was only one born female transsexual at the face to face meetings who stopped coming because she said the meetings were geared toward male cross dressers and male-to-female transsexuals. There were differences and discomfort between these two segments within meetings and in social networking.

All groups emphasized coping with emotionally difficult situations. Analysis found three sets of emotions: (1) solidarity and authenticity; (2) self-esteem and self-efficacy; (3) fear and anger. Self-narratives were used to portray individual's lives while stories were exchanged about relations with health professionals.

The authors argue that emotional work was only partly accomplished in groups, and that transgender activists and nascent social movement organizations (SMO) used motivational framing to promise targeted recruits a more permanent emotional resolution – one that would draw them into the movement. Support groups emphasize authenticity as a central problem, while SMOs emphasized oppression.

Participants had joined support groups to find relief from shame, fear, powerlessness, alienation, and inauthenticity. Techniques included learning how to pass and joking about fears. This interpersonal work was unsuccessful for many reasons. The emotional promises embedded in the SMOs resonated with the emotional desires of support group members. Therefore the authors argue that emotional resonance may fuel political consciousness-raising.

(45) Stewart, Greg M. and Gregory, Barry C. 1996. Themes of a long-term AIDS support group for gay men. *The Counseling Psychologist*. 24(2):285-303.
The co-facilitators of a five-year-old AIDS support group discuss the content themes (observational study). Support was gained by individuals telling their stories. It was common for group members

to avoid talking about their feelings. Members often had to be encouraged to reach beyond the sharing of medical information. They state that one might argue that a gay male with AIDS would have a well-defined set of emotional coping skills as he had to develop a repertoire of skills to manage his emotions around his marginalized position within society. But other researchers found that depending on how successful gay men with AIDS have been in embracing a positive gay identity may predicate the ability of group co-facilitators to assist members in drawing effective parallels between existing coping skills and those needed to respond to the new stresses from HIV.

For group members with lovers, a variety of support issues were evident. Some lovers were unable to provide their partners support because of their issues about HIV infection. Others were physically or emotionally unable to provide support because of their own HIV-related illnesses.

(46) Stewart, Miriam J., Hart, G., Mann, K., Jackson, S., Langille, L. and Reidy, M. 2001. Telephone support group interventions for persons with hemophilia and HIV/AIDS and family caregivers. *International Journal of Nursing Studies*. 38(2):209-225.
This is a qualitative study. Of interest in this pilot project in Quebec was that the men with hemophilia and HIV/AIDS (in their early 30s) stated that emotional support was most important even though they appreciated the informational support communicated in the group. In post-intervention interviews they frequently stressed the significance of different types: listening, sharing, feelings and experiences, expressing solidarity, and trusting. Caregiver data was not dis-aggregated by sex/gender.

(47) Taylor, Shelley E., Klein, L.C., Lewis, B.P., Gruenewald, T.L., Gurung, R.A.R., & Updegraff, J.A. 2000. Biobehavioral responses to stress in females: Tend-and befriend, not fight-or-flight. *Psychological Review*.107(3):411-429.
and
(48) Taylor, Shelley E., Klein, L.C., Lewis, B.P., Gruenewald, T.L., Gurung, R.A.R., & Updegraff, J.A. 2002. Sex differences in biobehavioral responses to threat: Reply to Geary and Flinn (2002). *Psychological Review*. 109(4):751-753.
These papers review both animal and human literature. The authors developed a tend-and-befriend position because they believe that existing models of stress obscured important biological and behavioural differences between the sexes and over generalized

evidence from men to women. Females seek and give social support at levels that are markedly, robustly, and qualitatively different from those of men. For example, women are more engaged in their social networks than are men. Men tend toward larger social groups than is true of women, and these groups are often organized around well-defined purposes or tasks. Although men orient toward and invest in a large number of social relationships, many of these emphasize hierarchies of status and power rather than intimate bonding. Female grouping tend to be smaller, and often have the establishment and maintenance of socio-emotional bonds at their core. Women in women's social groups show more affiliative behaviours, including smiling, disclosure, attention to others, and ingratiation, and they interact at closer physical distances than do men's groups.

The general model of fight-or-flight, is insufficiently precise to account for specific neuroendocrine and behavioural stress responses characteristic of women. The author ask whether sex differences in human behaviour would be better understood as differences in social roles rather than as evolved bio-behavioural responses. The tend-and-befriend pattern may be maintained not only by sex-linked neuroendocrine responses to stress but by social and cultural roles as well.

The study of stress will be well served by attention to men's and women's social and biological responses to stress – both the commonalities and the differences in their responses.

(49) Taylor, Verta. 1999. Gender and social movements: Gender processes in women's self-help movements. *Gender and Society*. 13(1):8-33.
This article draws on a case study of the postpartum depression self-help movement. The author suggests that examining the gender logic of a movement's mobilizing structures allows us to recognize the impact of gender processes. The crux of women's self-help is found in submerged networks or social movement communities that coalesce loosely around informal leadership and personal relationships stitched out of participants/ giving and getting emotional and other very individualized kinds of support. It is not uncommon for participants to use maternal metaphors to characterize the woman to woman support provided by self-help. But networks do more than simply provide individual support – the expression of emotions is a deliberate tool for change. That collective self-expression in politics is fundamental to women's self-help.

The context is the shifts in gender relations in American society, specifically the "change from the traditional family unit, where the man went to work and woman stayed home to raise children". The fact that there are class, race, and cultural differences among women and between women and men make the development of gender consciousness problematic. The author states that we need to look at how social movements contribute to the social construction of gender.

(50) Timko, Christine, Moos, R.H., Finney, J.W. & Connell, E.G. 2002. Gender difference in help-utilization and the 8-year course of alcohol abuse. *Addiction*. 97(7):877.
This study followed almost 500 participants during year one, 3 and 8 with an assessment inventory. Women benefited more than did men from more AA attendance during years 2-8 of follow-up. In the case of employment, more AA attendance was related to a greater likelihood of employment for men, and no change in employment for women. The authors cite early studies which suggest that AA's philosophy, involving acknowledgement of powerlessness over alcohol, lack of control over one's behaviour and one's dependence on a higher power to attain sobriety is easier for women to accept. Reference is also made to women's lower self esteem, the fact that AA is free (eliminating financial barriers) and anonymous. Anonymity may be particularly important for women due to the more powerful social stigma for women than men surrounding alcohol use.

There is some discussion of the gender differences in severity of alcoholism and treatment patterns. One reason to explain women's initial worse drinking patterns is that physicians tend to diagnose mental health problems rather than alcohol abuse. Women are more likely than men to attend AA during the first follow-up year after treatment.

(51) Volkers, Nancy. 1999. In coping with cancer, gender matters. *Journal of the National Cancer Institute*. 91(20):1712-1714.
This is an essay about communication styles and coping with cancer. Men are described as unwilling to enter support groups and more apt to keep things to themselves. Women tend to share personal experiences and encourage other women. The author suggests that support groups for men do exist, but have a different flavour than female-oriented groups.

(52) White, Barbara J. and Edward J. Madara. 2002. *The Self-Help Group Sourcebook: Your Guide to Community and Online Support Groups*. Seventh Edition. New Jersey: American Self-Help Group Clearinghouse. Page 86.
This is an American listing of self help groups prefaced by information about groups and a review of research. A short summary about sex differences theorizes that more women participate in self-help groups than men because more women under stress might be more prone to seek out other women in a support group. This is based upon research which states that women have a "tend and befriend" response to stress while men have a "fight or flight" response. See Taylor, S. E. et. al. 2000 [47].

(53) Williams, Fiona. 2004. Care, values and support in local self-help groups. *Social Policy & Society.* 3(4):431-438
Qualitative interviews inform this article about 'care' and 'values' in local self-help groups and voluntary organizations which mobilize around partnering and parenting in the UK. The very informality and commitment to developing a shared identity… sometimes unwittingly contributed to forms of social closure. There is a lack of involvement of racialized minority groups in smaller, more informal and less networked groups which were fairly uniformly white and mainly female. Sometimes there were groups for specific populations with "two cultures running along side by side". Where groups had become involved in wider networks, or started applying for funding, they had often been required to address perceived exclusivity. The non-involvement of men was striking. For some this reflected fixed gender differences. For other, men's involvement was more a reflection of men's changing emotional and practical investments in parenting and partnering, and where such involvement was high, or where it was threatened, then men did become involved.

(54) Wituk, Scott, Shepherd, M.D., Slavich,S., Warren, M.L., Meissen, G. 2000. A topography of self-help groups: An empirical analysis. *Social Work*, 45(2):157.
This study examines the member and group characteristics of 253 self-help groups. Researchers conducted telephone interviews with groups randomly selected from the Kansas Self-Help Network database. 38% of the groups assisted those with physical illness; 11% with disabilities, 10% mental health, 8% addictions and eating disorders, 8% parenting and 8% grief and bereavement. Group members were predominantly female (68%) and ethnic minority participation was 8.8%, similar to the percentage of population in the geographic region.

(55) Wolf, Alecia. 2000. Emotional expression online: Gender differences in emoticon use. *CyberPsychology & Behavior*. 3(5):827-833.
The sample comprised 3 unmoderated USENET support groups and a football related newsgroup. A quantitative analysis of emoticon use was used. Females were the overwhelming majority in an eating disorder support group; divorce and depression groups had a balanced mix of female and male; and the sports group was almost exclusively male.

In the predominantly female group the most salient finding is the absence of emoticons indicating teasing/sarcasm. Females use 7 of 11 meaning categories especially humor, solidarity/support, and assertion of positive feeling/thanks. The predominantly male group uses 3 of 11 meaning categories. Teasing/sarcasm and humor represent the only emoticon use expressing an emotive intent. In the mixed gender groups the most striking finding is the female use of teasing/sarcasm. In these groups the difference between male and female frequency of emoticon use was not statistically significant.

The changes that take place in emoticon use when moving from same-gender to mixed-gender newsgroups indicate that rather than the emotional expression of females being silenced or muted by male encoding of emoticons, males adopt the female standard of expressing more emotion. Furthermore, women have added dimensions including solidarity, support, assertion of positive feelings, and thanks, which were absent from the male-created definition of emoticons and their use.

(56) Wolkomir, Michelle. 2001. Emotion work, commitment, and the authentication of the self: The care of gay and ex-gay Christian support groups. *Journal of Contemporary Ethnography*. 30(3):305-334.
This qualitative study is based on interviews with thirty men. Men from the southeastern U.S. joined these particular groups (gay Christian and conservative ex-gay ministries) because each held out an emotional promise – either to rectify negative emotions or allow for the enactment of positive ones. Healing became the focal point of meetings with the group leader asking veteran members to recount their personal stories. Group members worked collectively to transform emotions to model appropriate (to each) group feelings. Emotion and identity work were mutually sustaining. The author believes that emotional work is, at times, identity work. Shared expression of emotions therefore allowed members to feel themselves to be part of a community; they were empowered to redefine themselves.