

Women and Health: Experiences In a Rural Regional Health Authority

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Executive Summary

As the health system gains a better understanding of the social dynamics of health and health care, there is greater recognition that health planning has much to gain from seeking input from women. As principal family caregivers and high users of health care, women have frequent and intimate contact with the health system. Furthermore, women as a population group are vulnerable; they are disproportionately affected by many social factors – such as poverty and violence – that put them at risk for ill health and bear a high burden of health problems linked to reproduction, mental health, family violence, and aging. The purpose of the study, therefore, was to seek guidance from women, based on their knowledge, opinions, and life experiences, to shape planning for women’s health and health services within Manitoba’s rural South Eastman regional health authority (RHA).

Methods

To give voice to South Eastman women, the RHA partnered with a number of local women’s groups to conduct a community-wide qualitative study. Between October 2000 and March 2001, 173 South Eastman women ages 19 to 85 years took part in a series of personal interviews (5), focus groups (21), and discussion groups (5) held in various communities throughout the region. Participants represented a wide range of backgrounds and viewpoints, including communities of women with special perspectives on health and health care, such as young adult women, senior women, francophone women, women with disabilities, immigrant women, women with experience of the mental health system, women with experience of domestic violence, and farm women.

Interviews, focus groups, and discussion groups explored women’s health by soliciting participants’ responses to three questions:

- What are the main women’s health issues in your community?
- What barriers are there in your community that stand in the way of women’s health and health care?

- How can South Eastman regional health authority best work with your community to improve women's health?

Women spoke from their own life experiences about health and interactions with the health care system, contributing their knowledge, opinions, personal stories, and recommendations. Each interview, focus group, and discussion group was tape recorded. The tapes were subsequently transcribed verbatim and analyzed, using standard qualitative research techniques, to delineate consistent themes. Every effort made in the presentation of the findings to describe participants' contributions in their own words.

Main Findings

Throughout the discussions, women made it clear that they consider health a priority item, that they see themselves in the traditional family caregiver/health manager roles, and that barriers to health and health care were the key issues they wanted to discuss. With remarkable consistency across all communities of women, participants identified a range of social and system factors that stand in the way of health and health care, limiting women's ability to take responsibility for their personal health and that of their families, to interact positively with the health system, and to gain access to necessary services. Despite women's diversity of backgrounds and experiences, there was agreement across all groups regarding fundamental needs for greater respect, for more accessible, holistic services, for better communications with health care providers, and for information and assistance finding the mutual support and services women need to deal with health problems. Women were also agreed on recommendations to the regional health authority for ways to work with communities to improve women's health, calling for a focus on women's health, greater access to quality information on women's health concerns, community advocacy, and systems to foster mutual support.

Policy Recommendations

Acknowledging gender as a determinant of health

- **Incorporate gender-based analysis as a routine component of decision-making.** This means not only ensuring that data for evidence-based decision-

making are collected and analyzed in sex-disaggregated form, where available, but examining policy and planning decisions, where appropriate, with an appreciation of gender variations to assess the potential for differential impacts on women and men.

- **Promote awareness and education on the role of gender in determining health.** Awareness and education should be targeted both to the public and to health personnel, at all levels within the system. Teaching should relate to the social dynamics of gender and to differential impacts on risks to health and responses to prevention and intervention. A holistic approach should be taken, considering health in the life context rather than focusing on specific diseases and conditions.

Acknowledging gender as a determinant of health services

- **Strengthen the processes that women value.** Women place particular value on key processes that enhance access to health and health services, namely taking individual responsibility for health, communicating successfully with health staff, and gaining entry to the health system and access to necessary services. Education and resources are required to help women develop and enhance skills around these processes and to equip staff with the appropriate knowledge and tools to give meaningful support to all health care consumers.
- **Acknowledge women's priorities.** This means respecting women's collective wisdom and life experiences and acting on their priorities and suggestions. Policy-making and planning should build on women's recommendations by working with communities to facilitate networking, mutual support systems, and advocacy mechanisms for women's health and health issues, as well as fostering effective communication and information exchange between health providers and consumers.
- **Involve consumers in health planning.** Consumer participation in planning should be part of the health system's quality management process. This means involving consumers at various stages of program and service planning, including needs assessment, design, implementation, and evaluation. The approach enables

the health system to benefit from consumer knowledge and experience in identifying and meeting community health needs, monitoring the appropriateness of services, assessing policy and planning decisions from key perspectives, including that of gender, and measuring effects in terms of health outcomes and consumer satisfaction.

- **Promote and support gender-oriented health services research.** There is very little information available to guide the health system in understanding the impacts of gender on health services, the interactions between gender and other determinants, and the effectiveness of interventions directed to improving health among men and women. In addition, each organization responsible for health service delivery is unique in terms of its structure and composition and the characteristics of the population served. Gender-oriented research should therefore be prioritized as a basic prerequisite to planning health services for women and for men, keeping in mind that population-specific research provides the best guide to organizational decision-making.
- **Promote awareness and education on the role of gender in determining health services.** Awareness and education should be targeted to the public and to health personnel at all levels throughout the system. Teaching should relate to the ways in which gender can impact both the delivery and receipt of health services, focusing on health behaviours, effective and sensitive communication, power relations, and the impacts of personal values and belief systems on interactions in health settings. Tools and resources should be developed to assist in the educational process.

Recognizing population diversity

- **Maintain a population-based, evidence-based approach to health policy-making and planning.** This approach, by taking into account population diversity with respect to life circumstances and life experiences, enables the tailoring of health services to address the very wide range of health and health care needs within gender groups.

Addressing system problems

- **Examine enhanced and alternative methods of service provision.** The effectiveness and quality of local programs and services should be subject to review incorporating consumer perspectives, and the cost-effectiveness of enhanced/alternative service models explored.

Acknowledgements

The willingness of South Eastman women to contribute time and effort to this project and their generosity in openly sharing experiences and insights on health is gratefully acknowledged. The wealth of information collected with their assistance offers valuable direction for the health of South Eastman women, families, and communities.

Thanks are also extended to the Prairie Women's Health Centre of Excellence (PWHCE) for the grant which made this research possible, to members of the research team, and to regional and allied staff who assisted with the focus and discussion group components and contributed helpful suggestions on earlier drafts.

What is truer than the truth? The story.

Old Jewish Proverb

The people interested in the results often don't get a chance to experience the groups firsthand. They don't get a chance to feel the delight, concern, pain, or indifference. They don't get to hear what makes people angry or what gives them hope. They don't hear the stories. So I become their storyteller. My role is to honor what people have shared and present it in a way that is useful.

Mary Anne Casey, Focus Group Moderator and Evaluation Consultant

Table of Contents

	Page
Executive Summary	iii
Acknowledgements	viii
Introduction	1
Methods	
Findings	
Health Issues	
Barriers to Women’s Health and Health Care	
Barriers to Taking Responsibility for Health	
Lack of Information	
Roles and Expectations	
Barriers to Communicating with the System	
Lack of Information	
Roles and Expectations	
Insensitivity	
Barriers to Gaining Access to Quality Services	
Lack of Information	
Stigma and Taboos	
System Organization and Inflexibility	
Women’s Recommendations	
Focus on Women’s Health	
Information	

Advocacy
Mutual Support
Discussion
Policy Recommendations
References

Appendix 1 Telephone Script
Appendix 2 Statement of Informed Consent
Appendix 3 Explanatory Letter
Appendix 4 Confirmation Letter

INTRODUCTION

As the health system reaches a better understanding of the social dynamics of health and health care, there is greater recognition that health planning has much to gain from seeking input from women. Women's health goes far beyond simple biology, relating instead to women's socially defined roles, characteristics, and positions within society:

- Women are the major family care providers and often the primary caregivers for children, spouses, and elderly and disabled relatives. Women are the principal managers of family health, responsible not only for knowing how to protect health and prevent illness, but for recognizing ill-health and seeking medical care when health problems arise.
- Women are the high users of health care. Women tend to use health services far more than men do, and this is true across the whole range of services, including medical, hospital, prescription, and preventive.
- Women as a population group are vulnerable, disproportionately affected by many factors detrimental to health, such as low income, limited job opportunities, and social isolation, and bearing a high burden of health problems linked to reproduction, mental health, family violence, and aging.

In October 1999, South Eastman Health/Santé Sud-Est Inc. and its community partners – Crow Wing Trail Farm Women's Institute, Eastman Crisis Centre, Rat River Health Council, Anxiety Disorders Association of Manitoba, and Central District Health Advisory Council – responded to a call for proposals by the Prairie Women's Health Centre of Excellence to conduct local research on women's health. The purpose of the research was to seek practical information – based on the knowledge, opinions, experiences, and suggestions of South Eastman women – for use by the regional health authority and other community agencies and groups for policy-making and planning around women's health and health services. Funding approval was received in April 2000.

BACKGROUND¹⁻¹⁰

South Eastman Health/Santé Sud-Est Inc. is one of several regional health authorities in Manitoba, established under the provincial Regional Health Authorities Act, which came into effect in 1997 (Figures 1 and 2). Regional health authorities are charged with responsibilities for assessing and prioritizing health needs of local residents, ensuring effective health planning and service delivery, and managing an integrated health care system within their own regions.

Figure 1. Manitoba Regional Health Authorities.

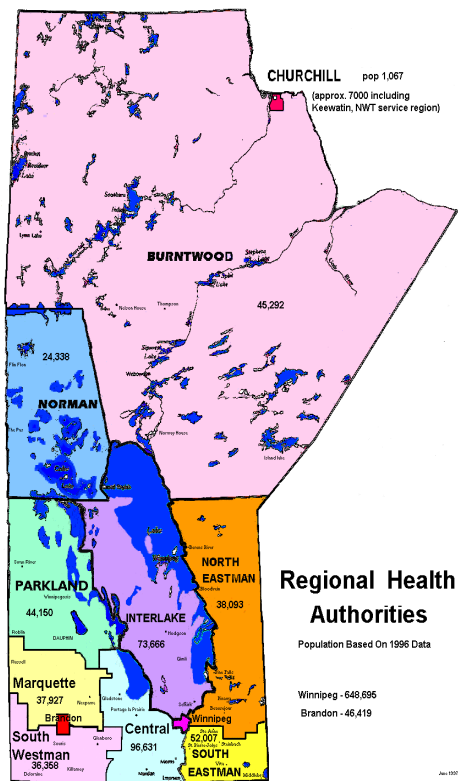
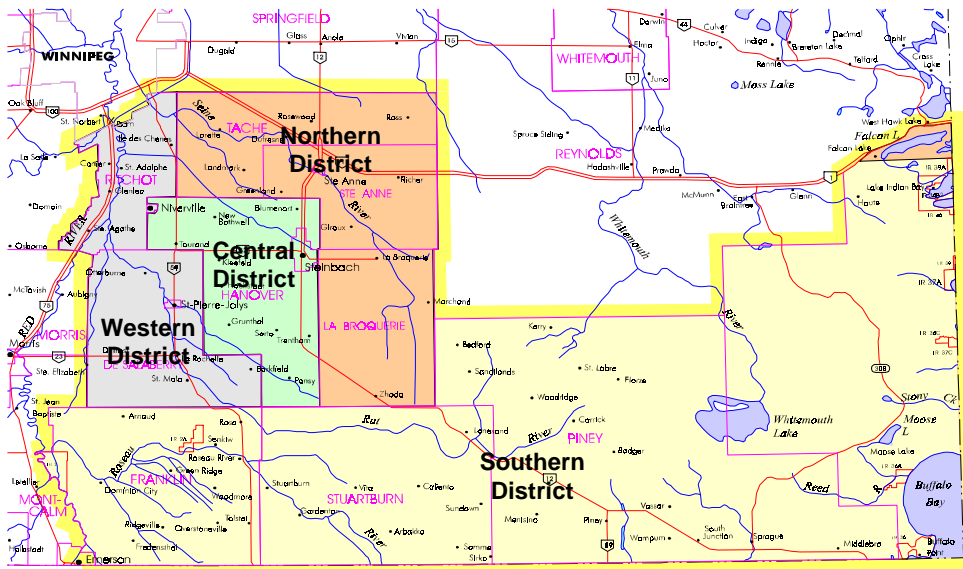


Figure 2. South Eastman Regional Health Authority and Planning Districts.



South Eastman community health assessment data focus attention on the health of women and highlight their considerable vulnerability. Demographic, socioeconomic, and health service data describe factors that place women at high risk for poor health, while women themselves report wide-ranging personal health concerns.

South Eastman is home to just over 26,500 women and girls. Approximately 6,500 (24 per cent) are under 15 years, with 17,000 (64 per cent) age 16-64, and 3,100 (12 per cent) age 65 or more. Approximately half reside rurally, on farms or acreages or in small hamlets, and half in larger communities. Overall, women and girls represent 49 per cent of South Eastman residents, but women's contribution to the population rises steadily with age until, by age 80+, they form nearly two-thirds of highly-vulnerable seniors. South Eastman is one of the few Manitoba RHAs experiencing population expansion. Projections indicate that, by 2025, the number of regional residents will rise 38 per cent, second only to the increase (44 per cent) predicted for the northernmost RHAs, Burntwood and Churchill. The number of adult women and men in South Eastman will increase 18 per cent by 2010 and 41 per cent by 2025. At the same time, the regional population, like others across Canada, is progressively aging. It is predicted that, by 2025, South Eastman residents age 75+ will exceed present population levels age 65+,

with the number of men age 80+ rising 26 per cent and the number of women age 80+, 74 per cent.

While relatively prosperous overall, the South Eastman population is not without socioeconomic variation. For example, one-third of residents age 75+ are women living alone, 40 per cent with income below the poverty line. One-third of all regional residents, including those age 15-44, have less than grade nine education and unemployment rates, although variable, are high in many areas. One-quarter of regional households report annual incomes below \$20,000, with figures ranging from 16 per cent in the Northern District to 41 per cent in the vast and sparsely-populated Southern District, where one-third of the labour force (both women and men) is employed in seasonal agricultural work, the population is aging (20 per cent age 65+), and community supports are few and dwindling. Premature mortality in the Southern District population is well above average for the region, as is the calculated level of socioeconomic risk for poor health, major components of which reflect risk to the health of women.

Single mothers head 10 per cent of South Eastman families. Three-quarters of South Eastman women with children are working, including two-thirds of women with children at home - a figure which rises to 90 per cent in the Southern District. Despite 1,100 employed women with children under age six, there are only 500 licensed day care spaces available across the region. Only 40 per cent of South Eastman women can expect to work full-time year-long, compared to 60 per cent of men, and women's wages, on average, are 35 per cent lower than men's. Women's employment opportunities tend to focus on traditional areas, with 55 per cent of women, but only 17 per cent of men, reporting clerical or sales occupations. On average, South Eastman women are twice as likely as men to provide significant, regular, unpaid care to children or seniors.

Health service statistics also give cause for concern. Only three of the region's 35 family physicians are women, yet women account for the majority of physician visits overall and for two-thirds of visits made by the age group 15-44. At the same time, women age 15-44 are prescribed anxiolytics and antidepressants at double the rate recorded for men. In

a 1998 region-wide survey, two-thirds of women responding called for increased and improved mental health services, 14 per cent reported needing help for stress experienced at home (compared to eight per cent of men), and around 15 per cent had consulted a professional in the past year concerning mental health problems, a figure rising to 25 per cent for the lowest income groups. Domestic violence is a growing problem in the region, yet only around 60 women annually access shelter services, very few from beyond a 50 mile radius.

Women's low participation in screening programs is a worry. Although screening programs for cervical and breast cancer are among the most effective preventive measures available, only three quarters of South Eastman women age 20-34, and half age 35-69, receive Pap tests every three years, and under 50 per cent of regional women aged 50+ are screened for breast cancer at the recommended two-year intervals. Recent information shows that screening rates are not only lower among older women, but markedly lower among rural women and women in poor socioeconomic circumstances.

Community consultation is an integral part of South Eastman's ongoing community health assessment. Since 1996, an extensive, region-wide consultation process – involving community consumer and provider meetings, focus groups, key informant interviews, and population-wide surveys – has solicited residents' experiences and opinions, across age, gender, and geographic groups, on the major factors influencing health in their communities.

Throughout the process, South Eastman women have clearly articulated concerns for their health and awareness of the many factors that adversely influence their health. Consistently mentioned have been the need for two incomes, the shortage of affordable child care, the burden of caring for aging parents, the ever-increasing expectations placed on women, multiple roles, multiple sources of stress, and the lack of support systems - mutual or professional - for coping, particularly with mental health problems. Through the detailed experiences related by groups of women, we have begun to see how the negative health effects of demographic and socioeconomic circumstances are mediated.

Women in religious communities, for example, have described restrictions on education and communication with the outside world that limit their knowledge of health and health services. Rural women in crisis have described several barriers which limit their access to the services and supports needed to leave violent situations. Long distances and lack of transportation restrict rural women's access to shelters. Low incomes limit access to counseling services. The lack of affordable housing makes it difficult for women to find accommodations for living independently. Many women have shared their problems communicating health concerns to male physicians, while older women across ethnic groups (Mennonite, French, Ukrainian) have reported that language and cultural differences present barriers to service and that changing social structures are undermining community support systems.

METHODS

Qualitative research methods¹¹⁻¹⁷ allowed South Eastman women to speak from their own life experiences and in their own words about health and interactions with the health care system.

*Qualitative research deals with words rather than numbers.*¹⁸

*Qualitative research tells why . . . searches for and describes structures and categories of thinking . . . If one needs to understand why people do (or don't do) something, if areas of consensus have to be delineated, then only qualitative methods are appropriate.*¹⁸

*Qualitative research attempts to describe the behavior and communication of a specific group as it occurs naturally.*¹⁹

*Qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.*²⁰

Data Sources and Participant Selection

Qualitative data were drawn from a region-wide series of focus groups, discussion groups, and personal interviews conducted among South Eastman women. Focus groups were held in each of the region's four planning districts to take into account South Eastman's geographic diversity. Focus groups also acknowledged communities of women with special perspectives on health and health care: young adult women, senior women, francophone women, women with disabilities, immigrant women, women with experience of the mental health system, women with experience of domestic violence, and farm women. The following definitions were applied in participant selection:

Farm: women actively involved in the operation of grain, livestock, or mixed farming.

Francophone: women identifying themselves as francophone, both culturally and linguistically.

Senior: women age 65 years or older.

Young adult: women age 19-25 years.

Mental health: women with personal or family experience of the mental health system.

Domestic violence: women with personal experience of domestic violence.

Disability: women with physical disability or chronic illness interfering with quality of life on a daily basis.

Immigrant: women immigrant to Canada within the past five years.

Personal interviews were conducted with key informants - women with extensive first-hand knowledge of health and the health system. Personal interviews were also offered to women who were unwilling or unable to take part in group interviews but nevertheless wished to participate in the research. Discussion groups were held in each planning district, involving women whose previous experience in the community consultation phase of South Eastman's community health assessment gave them knowledge of local health and health care issues and prior opportunity to formulate their viewpoints on women's health. Discussion group participants included women from the community at-large and women involved in the provision of health or health-related services.

Participant Recruitment

Participants were recruited through referral by members of the Community/Research Team or their respective community organizations; that is, by individuals with credibility and links among the various communities of women whose participation was sought. In the recruitment process, a woman familiar to the potential participant made initial telephone contact, using a standard telephone script (Appendix 1) to introduce the research, issue the initial invitation to participate, and seek permission for contact by the Study Coordinator.

Potential participants agreeing to further contact were called by the Study Coordinator, who sought verbal consent to participation, beginning with clear explanations about:

- The purpose of the research;
- The organization and who was involved;
- Possible outcomes, including benefits and potential harms;
- Measures to protect confidentiality and how these would be maintained;
- Reassurance that participation was completely voluntary and that no participant was obliged to answer any questions asked; women were free to refuse to participate or

cease participation at any time - no explanation was required and no repercussions would result;

- Participants would have access to the final report, with the option of receiving the report directly.

Women giving verbal consent to participate were asked to complete a written statement of informed consent (Appendix 2). This was forwarded to the participant by mail, together with an explanatory letter (Appendix 3). Each woman providing written informed consent was mailed a copy of the signed consent form together with a letter of confirmation, which reiterated project details and the date, time, and location of the interview (Appendix 4). A reminder telephone call was made the day before the scheduled interview.

Participation

In total, 173 South Eastman women ages 19-85 took part in the study: 129 women participated in focus groups (21), 39 women participated in discussion groups (5), and five women were interviewed individually (Table 1).

Table 1. Participant Profile

Setting	Community of Women	Number of Focus Groups/ Discussion Groups/ Interviews	Total Number of Participants
Focus Group	Farm	2	17
	Francophone	4	30
	Senior	4	28
	Young	2	8
	Mental Health	3	10
	Domestic Violence	2	10
	Disability	1	6
	Immigrant	3	20
Discussion Group	Central District	1	7
	Southern District	1	8
	Northern District	1	11
	Western District	1	7
	Health Care Provider	1	6
Personal Interview	-	5	5
TOTAL	-	31	173

Process

Personal interviews, focus groups, and discussion groups were held in various communities throughout South Eastman, with times and locations arranged for the convenience of participants and particular consideration given to personal safety for women in shelter and access for women with physical disabilities. In all venues, women were asked to consider three questions:

- What are the main women's health issues in your community?
- What barriers are there in your community that stand in the way of women's health and health care?
- How can South Eastman regional health authority best work with your community to improve women's health?

All interviews were led by the Study Coordinator. Focus group sessions represented facilitated group interviews guided by the Study Coordinator as moderator. The interviews explored women's health by soliciting participants' opinions, anecdotes, experiences, and impressions with regard to the three discussion questions. Field notes were taken by the research assistant to record discussion points and non-verbal reactions and interactions among participants; open-ended questions were used to guide the discussions. Personal interviews followed the same approach. Discussion group sessions used the nominal group process to seek participants' opinions on women's health and the three discussion questions, with particular emphasis on possible solutions. Each interview session was tape recorded. The tapes were transcribed verbatim and the transcripts checked by the Study Coordinator against the tapes to ensure completeness and accuracy.

Identification of Themes

Data were subsequently analyzed using standard qualitative research techniques to delineate consistent themes. Theme identification involved several steps: each transcript was reviewed line by line by the two principal investigators separately to elicit key words and concepts; from these initial analyses, broad categories of ideation emerged; direct

quotes and observational data from the interviews were then analyzed jointly for congruence with categories; themes and sub-themes were subsequently derived.

FINDINGS

Health Issues

As the discussions began and women organized their thoughts around health issues, these were characteristically framed in the context of illness and disease. Among topics of concern identified, mental health clearly took highest priority. In fact, as will become evident, mental health was perceived throughout the consultation process and across all communities of women as an area of distress, where life-altering problems are common, information and support in short supply, and the health care system generally failing to meet women's needs. Other subjects frequently mentioned were those with preventive potential, particularly in the areas of maternal and reproductive health, cardiovascular disease, and environmental health. Here there was often concern over the nature and level of health programming – particularly perinatal teaching and breast screening – together with the sense that concerted efforts are needed to reduce the health impacts of lifestyle factors and uncertainty over environmental monitoring and safety.

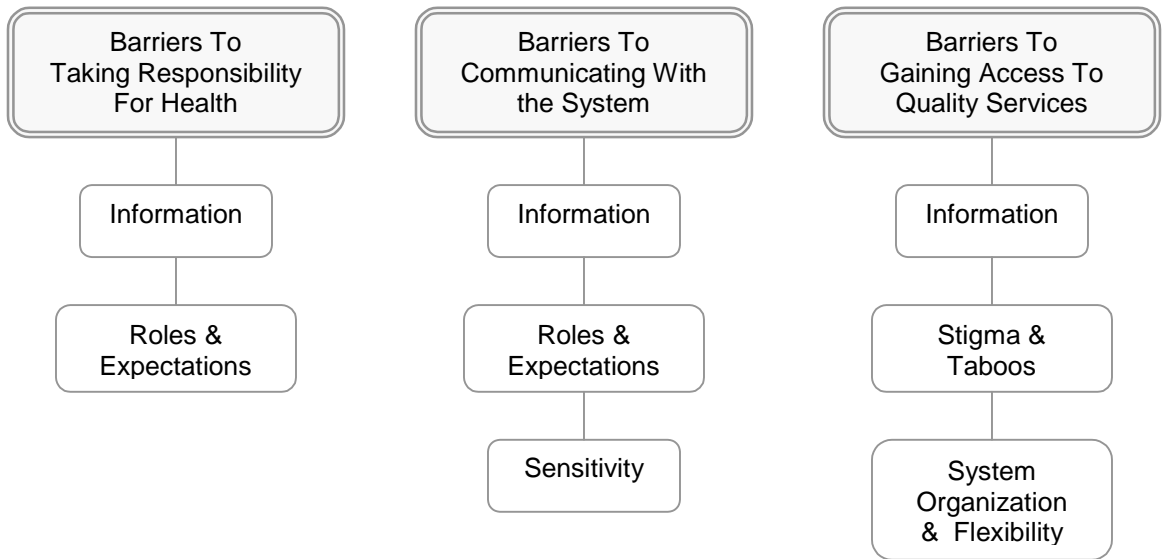
Invariably, however, the focus on illness was short-lived, with discussion shifting rapidly to the subject of health and the obstacles women face in achieving health for themselves and their families. It was evident from all of the interviews that South Eastman women see health as important; they value health as one of life's priority items. South Eastman women also view themselves in the roles in which they are traditionally cast – as the principal family care providers and the principal managers of family health. They feel the need to understand health problems, to be able to make informed health decisions and choices, to practise effective prevention, and to take the right steps in the face of illness.

Uppermost in women's minds were the factors that stand in the way of such processes. Women perceive a multitude of barriers to health and health care, many of which affect them disproportionately or even uniquely; these, for the vast majority of women, represented the biggest health issues of all.

Barriers to Women’s Health and Health Care

The barriers identified by women followed a number of very consistent themes in three broad areas, influencing women’s abilities to take responsibility for health, to communicate with the health care system, and to gain access to quality health services (Figure 3).

Figure 3. Thematic Framework.



Barriers to Taking Responsibility For Health

Lack of Information

Women want information about health. They want to understand health problems, how diseases behave, the relevant risk factors, and the preventive measures they should be taking. Lack of information is seen as the single biggest impediment to taking charge of one’s own health. As one woman noted, “People say we should take responsibility for our health, but to do this we need information and guidance as to where we can find the information we need.” Community after community of women stated, “We need information”, “Information is important”, “It’s important to have information available if you need it”, and “Knowledge is power”.

Even in the areas of maternal and reproductive health, where information is relatively plentiful, many women still feel vulnerable. One talked about birth control: “What does the pill really do? So many people don’t know what it actually does. There are so many myths about it”. “Both my mom and grandma had breast cancer,” said a young woman, “I think I’m at risk. Am I?” “My mother had breast cancer when she was 30,” said another, “No one has ever really taught me how to check my breasts. I look at my moles more than I check my breasts.” Another replied, “I’m not sure how to do it. The doctor asks if I’ve checked my breasts and I just say, ‘Uh-huh’.” Older women wanted information on breast cancer screening: “My mother had breast cancer but I was refused screening”; “I’m 40 years old but I was told I wasn’t old enough! What can I do?”; “I’m 69. I got a letter saying I’d be too old for the screening program in two years time. Don’t women over 70 get breast cancer?”

Women also talked about feeling ill-prepared for their roles as partners and mothers. Some stressed emotional factors: “When I got married, it was a shock. I thought it was going to be great; it wasn’t like I expected. You need to be better prepared. Younger women need to know about the emotional aspect when you are committed to someone.” A mature woman commented:

“Adolescents need to learn about the realities of relationships. This should be part of the high school curriculum. They only get the romantic view portrayed by soap operas and enter relationships totally unprepared. What a shock this often is!” “

Other women felt that when motherhood came they were ill-equipped for the realities: “You go into the hospital and the older nurse tells you to do this and the younger nurse tells you to do this and your mom’s telling you to do that and the doctor is yelling at the nurse for giving me the wrong thing, plus your own instincts are telling you to do something else!” “And what about when you get the baby home?” asked a young woman, “When do you feed them? When do you bathe them? I felt unprepared.” Others said, “At the hospital they asked me if I had changed the diaper and I was so overwhelmed, I hadn’t even thought of it! I felt inadequate” and “I walked out of the hospital thinking to myself, ‘Are you actually letting me take this kid home?’”

“Reproduction – it’s a big part of being a woman.” This general sentiment was echoed in comments reflecting the special needs that the reproductive years create for women, as this statement shows:

“There are critical times in a woman’s life that are fundamentally different . . . Women need to be nurtured while being the nurturer, because the infant places a tremendous burden on their physical and emotional well-being. If that isn’t understood, they are being put at risk. The male thinks, ‘I’m living it too’, but he isn’t living it.”

At the same time, maternal and reproductive health encompass only a portion of women’s health concerns. When women are regarded only in terms of motherhood, their other health needs tend to be forgotten. As one woman noted, “The only information I could find on women’s health was about pregnancy and having children. Personally, as a woman, an individual, this is very limited. If you’re having a baby or you’re a mom, you can probably find anything you need to know, but for your own health it is very difficult.” Another remarked, “Health Fairs – Baby First, Women and Infant Nutrition [programs] – all to do with children. And in a little room way back in the corner is the booth on mental health.” In the words of one young mother, linking the health needs of women and children “speaks for women not being really valued . . . women are only valued for their reproductive capacity”.

Women expressed appreciation for health information made readily available:

“The nurse went to the internet for information for me!”

“The public health nurse – anytime you have a question, just phone her up, if she doesn’t have the answer, she’ll get back to you.”

The health resource centre in ____: “They will get information pamphlets on every subject you can dream of, or organize workshops.”

Roles and Expectations

Women tend to view themselves as society sees them: as the principal care providers in the family and the principal managers of family health. Women regard themselves as capable (“We are the organizers”), as resilient (“I can do 15 things and not be stressed

and my husband does two things and he is stressed out”), and as placing a high value on health. One young woman spoke of convincing her husband to visit the doctor at least once a year: “That is my job. I make his appointments; if not, he wouldn’t go. Women take on that role. You have to do it for them”. This woman offered clarification:

“Women are at the centre – we are pivotal. We actually over-function because there is a strong sense of interconnectedness. If we are in a family of five, the husband is also there, but the woman tends to feel that each of those five are immediately connected to her, whereas the man can be somewhat isolated and detached.”

Many women find, however, that their personal health needs are relegated to the background, becoming almost invisible because they are in conflict with the needs of the family. Sentiments such as these were frequently expressed: “Women need to be strong to look after their families. Often our needs are forgotten by ourselves and others”, and, “Women look after other people but not necessarily themselves. It is their nature”.

The tendency for women to subjugate their own health needs has intensified along with the complexities of modern life. Throughout the consultation process, women spoke with emotion about their multiple roles and the stresses of balancing work, family, and caregiving roles. One young woman spoke of having little time for her own health: “When you have four kids, husband, house, pets, job, the last thing you think about is yourself. My husband goes faithfully to the chiropractor, but I couldn’t do that without feeling guilty and thinking what else I could do. Even [taking time to come] tonight is stressful”. Another woman talked about the pressures of farming life: “It’s hard to take time off to go to the doctor. I try to avoid it. I’ll go for the kids, but not for myself. You wait until winter – sometimes it’s too late”.

The following quotes further illustrate these ideas:

“Women are often invisible, forgotten.”

“Women are busy trying to keep all the roles straight, working and raising children, focusing on being superhuman . . . they’re not doing a very good job of looking after themselves.”



“Women’s stresses, multiple roles, caregiving, rushing around doing everything the other family members haven’t done. Elderly people get sick, who goes to deal with them? Is it sons really, really often? Not likely. It is more often daughters or daughters-in-law. It wears out women. It’s incredible what is going on in their lives. How come you’re not dead, never mind depressed?”

“[Women] make sure that their children are expertly cared for, that their house runs efficiently, that their jobs are well done, and yet they may show up at work ill for weeks before attending to themselves – ‘I don’t have time, I’ll get to that’ – and that is just the physical thing, that shows; but there are all kinds of things that happen that are much more hidden in terms of mental health.”

“Often women are the ones who have to stop working . . . she loses income and status and who she is as a person. That is a barrier. Women are seen as caregivers. That is part of the environment that women find themselves in. Especially the single woman. This is very strong in the Mennonite culture that it is the single daughter’s responsibility to care for aging parents. We are in a sandwiched spot – our needing to work for our own self but you should be at home looking after your parents.”

At the same time, many women consider that society in general places little value on the caregiver role, a belief brought forward in the comments “Women feel inferior, though they have a lot to contribute” and “Our job is simply to change diapers and make food”. Such ideas play themselves back as low self-esteem, evident in one woman’s rueful statement that “Religion belongs to the priest, health belongs to the physician, education belongs to the teacher, and I am a pawn”. For very many women, self-worth is measured in terms of caregiving, as this participant pointed out: “If my kids achieve well and perform well and my partner is happy and my in-laws are happy, I am a good person. When these things don’t go well, I have failed”. “But it’s still about ‘them’ and not about ‘me’”, she continued, “and then women’s self-esteem gets all tangled up in their ability to care for themselves. When women don’t value themselves, they tend to focus on taking care of others instead of dealing with their own issues.”

Women's awareness of these dynamics was evident throughout the consultation, along with a strong desire for change, evidenced in this comment: "These societal norms that it is the woman's job to look after everyone's health! Society needs to change! How long is it going to take? Maybe our daughters' daughters." "I don't think women choose," said one participant, "Women accept their lot ." "If it isn't a choice, but an expectation, then it isn't good", replied another, "You can only make choice in a free environment." Many women are actively working for change in their own situations. "I have a responsibility to my future daughters-in-law", said one, "I have four sons. I have always worked. They have made their own lunches, et cetera. They should know what it means to have a working wife!" Another woman stated, "I have always tried to tell [my daughter] that she is an important individual. She is a woman and it is good."

Women spoke of dealing with multiple roles and expectations:

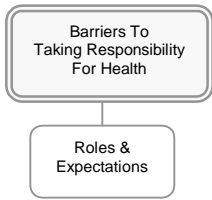
"I have a job to teach my daughter that it can be different. She will always work; she will have to shuffle the role of mother and all these different roles we assume that add stress to our lives. I have to give up some of these roles and I have to make a conscious effort . . . we have to make a conscious effort to step out of the roles."

"I know we have heart disease in the family – I have to pull myself out of all these roles. I know I am at risk, so I consciously do something about it. I know I can't play all these roles, like Playboy's centerfold of Miss September, Betty Crocker, and Martha Stewart, and so on. Sorry, can't do them all! Every now and then, I do a really good Peg Bundy . . . pull out of the multi-role circus."

"What I like", said one woman, a health provider, "is hearing about women raising children to be more independent and moving more towards the idea that women are strong and capable and men can be sensitive . . . It causes a shift in expectations for every other relationship they have; it changes the lives of those people." To which, her companions added these comments:

"In the real world, there is a whole majority of women who can't do that."

"How many men want to dirty their hands? It's women's work. It also involves a lot of tears, so men say, 'Okay, I'm out of here'."



“It would be nice if we could say to those men in our lives, the elders, the brothers, ‘You should be looking after your grandmother and grandfather, you need the experience. Go for mastery! Do it for the rest of your life’.”

Barriers to Communicating With the System

Lack of Information

When it comes to actually seeking health care – advice, direction, or solutions to health problems – the task of communicating with the health system can present formidable challenges. Interacting with the system on any level – from securing the appointment, to presenting the history of the complaint, grasping the test requirements and results, understanding diagnoses and treatments – requires a fair knowledge of how the health system functions and good communication skills. Many women are ill-prepared for the task.

The first challenge in communication is gaining access. “I think that the health care system in general is pretty daunting for people,” said one woman, “not very user friendly, very intimidating.” “How can you get through the receptionist to talk to the doctor?”, asked another woman, “Sometimes it is like an impenetrable wall.” Automated messaging has imposed a significant new barrier to access and is a particular problem for seniors. “It cuts them off rather than enabling them”, was one comment, “What kind of message are we giving the elderly? . . . Human contact is critical . . . You want the person on the other end to understand and confirm.” As one participant remarked, “Many women give up when they don’t get help with the first phone call. It takes a lot of energy.”

Women feel the need for assistance in managing the system. As one older woman stated, “We need qualified resource people to open doors for us.” Consequently, the knowledge and experience of a family member or friend is often sought. This woman summed up the problem:

“If you don’t have a contact within the health care system, you don’t know what to do – you need a relative or friend who knows how it works and who to ask when you need information. If you don’t have that person and the issue is too small to go to the doctor



with, you live in ignorance – you have to make a judgment about going to the doctor; you might go, but you might wait longer than you should.”

Concerns for women without advocacy mechanisms are illustrated in the words of these women, both nurses:

“When my mother-in-law is ill, I am the first one called . . . to figure out which part of the system will fix the problem. What happens to women who don’t have someone involved in health care amongst their family members? If I am a person who doesn’t know where to find the answers, but I’m not confident to call someone who doesn’t know me, what if I ask a dumb question? I don’t think I will bother finding out how to connect with a counselor even if I am feeling lousy. I have concerns about that.”

“It was only when I was no longer in the [nursing] field, and encountering people who weren’t, that I realized I was getting special treatment because of connections that I had, with personal friends who knew doctors. If I didn’t know the specialist, they did, and I had assumed that this was as it should be and how it was for others.”

In addition, a retired nurse stated: “Navigating the system is really difficult. How do people who don’t have a relative in health care manage? They just stumble along in the hope of finding a provider who is competent and compassionate.”

Communicating with the system can in fact be so threatening that it deters many women from pursuing access to help. As these women pointed out:

“Sometimes women choose not to be served rather than be intimidated. That creates a vicious cycle: if I’m not feeling well, I might be able to sort things out if I could just talk to someone, but if I don’t sort that out then there are the long-term ripple effects of all the other stuff that comes along as a result of not taking care of the initial things.”

“In many cases, women are the last to seek care for themselves because they are too busy taking care of everybody else. In some instances they are again often downtrodden, threatened, and have no self-confidence, so it becomes more difficult for them to access even the things that are available to them. And in the case of the timid and shy, all they need is one put-off to do the job.”

Roles and Expectations

When it comes to communicating one-on-one with health care providers, women feel strongly that they bear a disproportionate share of the responsibility for making it work. Concern tends to focus on physicians, as primary health contacts, and is often related to factors that constrain opportunities for successful communication.

Time is a barrier frequently mentioned. “I wait 2-3 weeks for a 15-minute appointment to tell the reader’s digest version of my story”, said one woman. A young woman remarked, “If you don’t know what you want, they rush you. When I go to the doctor, I have to have a list.” Negative perceptions among senior women included “I feel the doctor wants to get rid of me” and “Physicians are too busy to listen to us, so they send us away with a prescription”. A woman who felt very rushed at her follow-up exam after breast cancer surgery expressed her feelings of indignation: “Hey, this is my life!”.

Women often perceive that the flow of information is restricted. “Why do we have to ask?” queried one young woman, “What if we don’t ask? Will they tell us?” Another stated, “The time factor is important for asking questions. If they would only say, ‘Anything else?’.” A senior woman commented, “When we have tests, we’re never sure if the results will be communicated. They say, ‘We’ll let you know if any follow-up is required.’ So we don’t call. At the next visit, months later, he reviews your chart and says, ‘Oops, we forgot to tell you’. This is quite frightening.”

A retired nurse related her personal experiences with communication around follow-up to a health event:

“All anybody ever told me were generalities: ‘Your body will tell you. Listen to your body. Walking is good.’ Duh! Sorry! Maybe my expectations are too high? But see, that is something I never learned as an acute care nurse. I never knew what happened to people once they went home. Stay well? How? Beats me! Like really. We had our teaching sheet. Sorry, that’s it! Again, then I went on net and got stuff from the Mayo Clinic and some of it was helpful. But still, I would have liked to have had some of the doctors that I saw either sit down and answer those questions or refer me someplace if

they didn't have time. But that never, ever happened. All they kept saying is how wonderfully well you're doing. Well, that was by guess and by golly. And at first my body did tell me, that if I didn't sit down or lie down I would fall down. It was probably the month of December and no one told me I would feel like that except my daughter-in-law who worked in a stroke recovery ward as an RN. 'It's normal,' she said, 'You will be more tired than you have ever been in your entire life.' No one told me that until she did. . . . If she hadn't have been here at Christmas, would I ever have been told? . . . Once your acute phase is over, you're on your own . . . And that's bad."

For many women, the health care encounter is very threatening. "We feel intimidated," said one senior woman. Commenting further on this general perception, these woman said:

"One thing that I think needs to be addressed is that people in positions of authority should be very careful how they deal with people. Maybe they are getting instructions, I don't know. I've noticed it in the doctor's office. The way the people, I don't know who they are, some are nurses and some are not, I mean secretaries, maybe they're being told, No, you can't talk to him, make an appointment. It isn't so much what they say as how they say it. The tone."

"Women feel intimidated in the doctor's office. I can imagine them sitting there and thinking, 'Well, the doctor said,' and they walk away because it was a man telling them, 'It's nothing, don't worry'."

Many women are reluctant to question physicians or to ask for second opinions. Some are afraid of hearing the answer: "If I ask the question, I will get bad news". Others are too embarrassed to admit that they don't know or don't understand. Said one woman, "You feel like you should know about these things and it is embarrassing to ask. You think everyone else knows." In general, women stand in awe of the physician. "Women won't say anything to their doctor," said one woman, "They don't feel comfortable . . . You don't go against their brains. They are the experts." Another said, "Women need to be assertive with those in positions of authority, to say 'I do not agree'." A nurse commented, "I have seen women go back again and again because 'something is wrong

with my child', but wouldn't do it for themselves. They will not use the same level of assertiveness for themselves." A minority of women adopt a more aggressive stand: "Whenever you are seeing a physician, whatever he suggests you take as the gospel, not realizing that you can question what he's suggesting. They aren't little demigods, they're just people who went to school" and "You have to keep asking questions, over and over again until you get an answer, even if you feel like a pest". Two women related their personal solutions: "I always get a copy of my blood test. I ask for it, and they fax it to me. . . It is my body, so I get all my reports. . . You have to be assertive" and "You have to be assertive. You almost have to tell the doctor what you want done. You have to take your health into your own hands . . . They are as good as what you give them. But they have to be willing to listen".

Conflict with the system can be a considerable source of stress, as this woman, principal caregiver to her home-bound husband, pointed out: "As a caregiver, as somebody who is already under stress, I can tell you that the biggest burden you can get is conflict and confrontation from those you believe are there to help you. In some cases, fear has power over you." There were other comments in a similar vein:

"One of my biggest stresses as [my husband] became acutely ill was to say 'This is what we want' and have people say 'We don't do that', and then you ask, 'Why not?'. But now, finally, we have reached the right people. This is the positive, that there is eventually somebody out there who listens to what you say and decides that maybe it is not that unreasonable and agrees to help you. And then, usually, good things happen. But I'm thinking, if I had that much trouble, what chance does this little old lady with no supports stand?"

"I think there are far too many women with low self images that the slightest thing can turn them off and we have to be careful that the caregivers again are not the deterrent. We need to be more conscious of that. The reigning conditions in the hospital are not conducive to that. People have been short-staffed, people have been extra shifting, all of those things which are certainly not conducive."

Controlling behaviour only serves to exacerbate negative feelings, as this story illustrates:

“I accompanied my mother-in-law to the emergency room when she had chest pain. I was treated very poorly by a male physician and I was very angry . . . When I asked the physician, ‘What shall I tell my father-in-law?’, his answer was, ‘Tell him she is spending the night in the hospital’, in a tone that implied that this was all I needed to know. I had no right to know what was going on. I felt whacked over the head and the physician meant, ‘How dare you ask me! How dare you challenge me this way!’. And I am a person who understands the system and I wonder how others manage who may not have this knowledge and are treated in this way when they are most fearful and vulnerable. This type of treatment certainly would not encourage people to seek out information or help in the future. . . I know that women’s health is more than just about how we serve women when they get to health service settings but at the same time, if we really want to serve people in terms of getting them healthy and well, we have to do a better job at the point of entry to health services.”

This woman described her negative perceptions of the medical community:

“Male-bound tradition, the old boys’ club . . . It is an impenetrable wall for many women. There is so much strength that comes from that uniting of ideas and attitudes. It takes an incredible opposing strength. A lone woman going into a doctor’s office . . . you can go in with your questions, so that you’re prepared and hold your head together, but that still doesn’t mean that you will change his attitude or have him be more open. You can be prepared when you go to the doctor, but that might not mean that it will change his mind.”

A fellow participant replied:

“It’s really good that you mention this strength and we have to learn from this model. We should learn from that binding together. This is what *we* have to do not to let that barrier affect us. *My strength will strengthen you.* It ‘s a good idea to have women go together to the doctor to really build up that strength. . . . It ‘s a good way not to see the medical profession just as a negative, but something we can learn from. If we knock a couple of times on the wall and it doesn’t open, we go over the wall. Take the next level, and take your ladder.”

A major issue for very many women is the sense of not being able to get their message across *because* they are women. Commonly, it seems, women feel that they are either not heard or not taken seriously. “I feel less listened to because I am a woman, not only about health”, said one, “Take your car in and they won’t listen; I sat on a hockey committee and wasn’t listened to; go to the doctor, and they don’t listen to a woman either.”

Similar sentiments were frequently expressed:

“My husband had to call.”

“The mother asking for help doesn’t get heard.”

“They don’t listen to women. That is what angered me the most . . . They will listen to your husband.”

“They don’t take the woman’s word for it when the woman knows something is wrong. That is a big concern. You have to insist.”

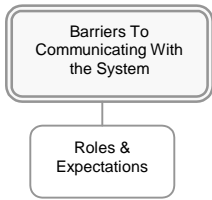
“I was raised in a time when women weren’t listened to that much and there are a lot of women like that . . . I once told the psychiatrist I disagreed with him . . . I wasn’t heard. And I never went back. It went in one ear and out the other. Maybe it would have been different if my husband was there.”

“Women have made a lot of progress but there is a long way to go. I don’t think we ever will be listened to like men.”

Women also perceive that the medical approach to their problems differs from that experienced by men. Women say they are regarded as “emotional”, their problems frequently attributed to “hormonal imbalance”, “menopause” or “stress” and thereby played down. One woman illustrated her views on this subject as follows:

“If a man and a woman go to a medical clinic with identical symptoms of a heart attack, the guy will get whipped into the cardiac unit. With the woman, they’ll sit and yap for three quarters of an hour asking, ‘Are you stressed?’”

Another woman, who spoke of the reality of stress in women’s lives, also voiced her concerns about differential management:



“Women’s mental health, like stress-induced anxiety – Is it being treated? Is it being recognized by the medical profession? Am I getting the same kind of treatment for the same kind of symptoms? Am I getting the same kinds of tests as a man would?”

When good communication is achieved, the results are very positive, as these women’s comments illustrate:

“My doctor actually lets me call her. She has been very good.”

“My doctor asks me if I have more questions.”

“My doctor and health nurse have been great; they offer any kind of information they have. My mom is in the hospital and the nurses are wonderful.”

“My doctor has been very accommodating – even though she is busy. I may have to wait, but she is also willing to give up her lunch time.”

“My physician is my friend. It takes time for both parties to get to know each other.”

Insensitivity

The degree to which communication is sensitive to women’s needs has a profound effect on confidence, satisfaction, and the perceived quality of health care encounters.

Most women, for example, believe they can communicate more easily and effectively when the doctor is a woman. A senior woman describing her physician said, “She gives me choices; she is a woman; she is gentle”. “A female doctor understands,” stated a young woman. Another said, “I wouldn’t want to talk about this [reproductive health] with a man. A woman understands you better, they sympathize. Somehow we all feel the same thing. There are good male doctors but, with certain issues, it is better to have a female doctor.” An older woman expressed a similar opinion: “I would like a woman doctor because I don’t feel comfortable with a male doctor. . . My daughters, too, feel more comfortable with a female doctor. . . It is for comfort.” “I was in an accident,” said another, “The female doctor said, ‘We know there is pain, but we don’t know what to do’. The male doctor said, ‘You’re not in pain, it’s in your head’. The response was different than from the woman. She said to make sure to let them know how you feel, but

you can't." The difficulty of accessing services in a region where only four of 34 family physicians are women was frequently mentioned:

"It is good to have somebody who will listen. Women talking to women. It would be good to have a female gynecologist here."

"There are female doctors but it's hard to get in. The only way you can get in is if you get on a list and you get sick and she is on call."

"I was not being listened to by my physician, so I went to the Women's Health Clinic. I spoke to a female physician and felt that I had been understood by a physician for the first time in my life. My appointment lasted for half an hour. I asked her to refer me to a female gynecologist and a female GP. I was told that it would be very difficult to find one. Why? They are all burned out."

However, as some women pointed out, achieving good communication depends on more than just provider gender:

"The gender and age of the physician is secondary to competence."

"Just that they are female doesn't mean that they listen. My doctor is male and he is good . . . All male doctors aren't evil."

"Women need to feel that somebody out there in this world is willing to hear them. One woman started crying, when I said, 'I think you're trying really hard and you're doing everything you can'. She hadn't experienced that before."

"Nobody is perfect."

Women from culturally-distinct communities expressed very strong desire for services delivered in their home language. This is an important issue for South Eastman, where around one-third of families record English as their second language and the number of newly-immigrant residents is steadily increasing. One woman recently arrived from Germany remarked, "It is difficult when we don't understand each other, especially when it is something serious. We can't always take a translator. Language is our problem." An immigrant woman from Paraguay described this situation: "The baby was 11 days old when he started having seizures and they found there was bleeding in his brain and he had to go to intensive care in the city and all the doctors were impatient and

nobody could explain. And they used so many medical terms we couldn't understand".

Another German woman told this story:

"We looked for a German doctor and in the hospital for some German nurses. It was important. I know that from my first baby until the youngest one it was improvement for me, that it was easier for me. I was just thinking that I want to go home because it was too hard. But the nurse was really good and this really helped too because when my first child was born she came and rubbed my back and this was like she could be my mom. This gave me help."

Language is important, not simply for the practical aspects of communication but because the successful exchange of ideas and sensitive information requires both linguistic and cultural compatibility. Two women of francophone background offered their interpretations: "When you are experiencing stress, tragic circumstances, it is difficult to express yourself in another language. Emotions are not easily translated. You feel awkward, ill at ease. It just isn't the same", and, "Going to _____ is not only another language, it is another culture. We need to be with people who understand our roots, where we are coming from".

Many women also mentioned 'provider-speak', the health care dialect that intersperses high-level language with health terminology and obscures explanations and instructions. Typical comments included: "A doctor has an education and uses big words. He should simplify things when he explains things to us" and "[Doctors] assume that you understand when they talk about diagnoses and treatment. I understand most of what they say and nod. But I'm an educated woman and I ask questions. I wonder, would they stop and ask if another woman didn't say anything?".

Among women with poor social and/or verbal skills, communication problems are more frequent and severe. Mutual frustration and anger not uncommonly lead to adversarial situations. Speaking of victims of domestic violence, a crisis centre worker noted, "These women often have social interaction problems – they don't always know the polite way of doing things and, especially if they are not verbal or if they don't know the

language, they run into problems – they don't always receive the same level of service.” “I worked with a woman who had epilepsy”, said another woman, “She came from a poor family. Her verbal skills weren't very good and she couldn't do things in socially acceptable ways. She was prone to anger. So her interactions with the medical profession were quite abrupt and not sympathetic. She had a history with them.” Yet another participant said, “They penalize angry women because women are not supposed to be angry. One woman expressed anger towards the doctor and he wanted to institutionalize her. Like, how dare you be angry towards the doctor, and how dare you be a woman and say what you said! You can't be angry with your doctor, or you're nuts!”

Thoughtlessness and sometimes disrespect for women's feelings may also play a major role in communication problems. This woman talked about receiving bad news: “The doctor told my friend on the phone that she had cancer. She got her results on the phone”. “I was called into the doctor's office alone,” replied a woman with breast cancer, “I wished I'd had my husband along.” Another woman, under the care of her physician for “burn-out”, acted out his sweeping entrance and cheerful greeting, “And how are we today?”. A woman who works in a crisis centre related this story concerning a client:

“One day she had a seizure and cracked open her skull. I took her to the hospital and the doctor stitched her up. He was very derogatory. She had balance problems. ‘Quit fooling around,’ he said, ‘You have to sit still. Sit still!’ Had it been a more important member of society, he wouldn't have been saying these things. Had it been someone more respected, or a man, something more would have been done.”

This participant related another woman's experience following childbirth:

“When she delivered her baby, she ripped, and was devastated when the doctor turned and said to her husband, ‘I'll put in an extra stitch, just for you’. They wouldn't say anything like that to a man.”

Barriers to Gaining Access To Quality Services

Lack of Information

Information about the services and options available to women is poorly disseminated and often difficult to track down. One woman commented, “Information is hidden.”

Another said:

“Information is very hard to find. You’re just a housewife and you’re at home with small kids all the time and you really need to talk to someone. You pick up the phone, but you don’t know where to call. So you call the public health nurse. She gives you a number to call and no one answers or they refer you back to the nurse. Or nobody gives you information, or they say call Winnipeg. And when you call Winnipeg, they say, ‘You live outside of Winnipeg. Don’t you have any services in your region?’”

As the following comments point out, women are often looking for information at a time when they are most vulnerable:

“Support. You have to have first of all the energy to seek it out. And most times you don’t.”

“I’m not sure that women know what the ‘menu of services’ is, and now they are feeling lousy and they have to go searching for the menu. This is just too much for them. But if they knew it might prevent a whole host of other things in the long run.”

“But they need to feel welcome,” she continued, “I know many women who are intimidated by many things, and it doesn’t take very much for them not to go and seek out information because ‘I don’t want to be seen as not knowing’. It is important for people to feel invited”.

Finding information is difficult even when the target of inquiry is the health care system itself. “The doctor gave me a couple of names”, said a physically disabled woman, “but sometimes you need more help than just phone numbers.” Another woman said, “I found out about community mental health when I was at the lowest. How come I didn’t know about it before? Maybe I could have prevented it.” One participant spoke of the help she received for panic attacks through ADAM (Anxiety Disorders Association of Manitoba): “ADAM was great. But it was around for a long time before I heard about it”. This

prompted an angry response from a woman in the same group: “ADAM? I’ve never heard about it ! And I get panic attacks!” Other comments related to accessing information on mental health services included:

“Our first encounter with a mental health worker was four years ago. It would have been nice to get a package of information: doctors that are experts, respite, and proctors. We only found out about respite six months ago. We should have been offered that when my son was four. You need that information. We needed that. It affects the whole family.”

“We brought our son in to see _____; it was a very bad experience. They didn’t tell us about the support group. We found out from a poster on the wall in the lobby . . . I don’t know what we would have done without the support group.”

“I have told people about this [community mental health] service . . . It is such a good service, and it is right here. It is like a hidden treasure.”

It seems that often the locus of responsibility for providing information simply is not clear:

“Who tells the woman newly-diagnosed with breast cancer that there is a breast cancer support group, how to get in touch with them?”

“Sometimes the resources are not well informed. You would think in the internet age you’d take time to get information.”

“The doctor thinks that his only role is to give pills . . . rarely, rarely do they say ‘Here’s a support group’ or ‘Here’s a web site with information on managing symptoms’.”

“The doctor could have information about the groups, then it is easier to contact them.”

“I was lucky to find a doctor who . . . has a lot of information and she counsels me.”

“The pharmacist sometimes knows more than the doctor about medication. They also do some counseling on your medication. He will research information he is unsure about.”

“If someone isn’t tolerant, you won’t get information.”

It was noted, too, that women's success in information-seeking and -finding often relates back to their societal roles:

“Sometimes women are much better at seeking help for others than for themselves. We need different skills and we face different obstacles when the help is for ourselves.”

Stigma and Taboos

Stigma is clearly alive and well in rural communities. Stigma not only prevents women from seeking help for their problems but prevents other women from offering support or sharing their personal experiences. This comment by a disabled woman reflected participants' general feelings:

“Accessing services in small communities is difficult. People see you walking into the office. It's uncomfortable, especially if you have grown up in the community. Rumours fly. The lack of privacy can be a deterrent.”

Two women from small francophone communities made these observations:

“Stress, family breakdown . . . women can't discuss these things because of small town gossip.”

“Our upbringing causes us to hold back in reaching out to others. We're afraid that they will think we're meddling. This is small town culture.”

Stigma is particularly severe when it comes to mental health. “I can't go to [my home community] to get help”, said one woman, “It 's too small.” Another woman spoke of her reluctance to seek help for intermittent mental health concerns: “Going would mean opening the case, but I just need help occasionally . . . I don't want to be put on caseload.” A mother, talking at length about difficulties accessing mental health services for her son, remarked, “In 1999, I was diagnosed with cancer of the uterus. I got help right away. On the other hand, it took 14 years to get help for my schizophrenic son.” Stigma also prevents women from accessing support, as this woman noted: “The self-help groups should be overflowing with women, but many don't seek help because of the stigma that still exists.”

Women spoke of misunderstanding and fear associated with mental illness:

“Don’t be scared to go to a support group. There is a stigma. But just to be listened to and be believed is a relief.”

“You have to erase the stigma that’s attached to [mental health] problems. You shouldn’t have to be embarrassed; there isn’t anything wrong with getting help for it. The stigma is why there isn’t enough information around.”

“You always feel what your child does. It reflects on you. But there are people who don’t want to understand. They think you have done something to your child.”

“This woman said to me, ‘Well, God didn’t make his brain any different!’. Like it was something I’d done to him.”

“Our schizophrenia society has a booth at the mall once a year. Nobody will go near it. People are afraid of it.”

Women spoke too about community attitudes and biases. “There’s a lot of labeling going on”, one woman said, “This town is really small”. Another agreed: “There are a lot of closed minds”. A young woman spoke of religious attitudes: “Lots of non-Christian people are having problems but they won’t come [to our youth centre] because they think they will get preached at”. Anger was expressed at the way community opinion can damage women’s lives:

“This community is very pro-life and that’s their choice, but I believe they shouldn’t create barriers for women who want information and services. I think that’s discrimination.”

“The stigma of being separated in an environment where being a married woman is valued and staying in relationships, no matter what, is strong. It’s horrific.”

Health providers, too, are seen to bring their personal attitudes and biases to bear in professional relationships:

“Some doctors will refer women for abortions; others flatly refuse to refer them and actually provide barriers to accessing information. Their personal views shouldn’t



interfere with care. If this was cancer, would the doctor say, ‘I don’t believe in cancer treatment’?’”

“And even public health nurses present their biases on abortion and pro-life issues!”

“In this area, you are classified as such a bad person if you are having sex. It took me a pregnancy before going on the pill. I felt I had to be defensive when I asked my doctor for the pill before I was getting married. It shouldn’t be like that.”

These women spoke from their familiarity with domestic violence:

“These small communities are incestuous in terms of labeling and imposing values. Sometimes it’s not the abuse by the partners that’s really harmful emotionally, it’s the doctors, the nurses, the people who are meant to be helping who are doing terrible damage.”

“Women who need information . . . how to go on social assistance . . . who do you phone? You don’t deal with that on a regular basis. You can’t talk to your friends or family because of the stigma.”

“In this community there is a certain level of classism and value judgment. Health professionals are mostly from this area and project their value system onto the clients. If women don’t meet the criteria, then things aren’t forthcoming. Women who don’t fit have to work a lot harder to advocate to get resources. It’s like they have to earn it.”

In addition, there are some subjects considered too unacceptable to address openly.

Sexuality is foremost, as this women noted:

“There’s denial – no one in this town has an STD, no one in this town has HIV, no one in this town is gay or lesbian. Even if someone admits to any of these, people pretend not to hear. Women are saying things and are not really being heard.”

Many women spoke of the taboos surrounding birth control. “I work in the school system,” said an older woman, “and a big concern is teen pregnancy. The kids are hiding it. They’re scared the physician will tell their parents if they ask for birth control. They’re scared to go to the counselors.” These young women elaborated:



“Most teenagers who are having sex don’t use birth control. Maybe we need more information in school, or a centre where you can get free condoms et cetera. It’s not open to talk about. It’s hush-hush.”

“Buying condoms is embarrassing, because someone you know might be working there or know your parents.”

“There has to be education. The rate of people being sexually active won’t decrease because of more education, but it will be safe. I understand where people are coming from, when they think you are putting ideas into young people’s heads. You have to teach your kid to be a strong person.”

Women spoke frequently of communities’ reluctance to acknowledge their poor.

“Poverty is a reality that just isn’t addressed,” said a young single mother, “I haven’t gone to the food bank yet and I’m proud of that.” “There’s no subsidized housing for single women and this is very discriminatory,” said a women’s crisis centre worker, “It’s only available to women who have children or who are permanently disabled.” The lack of appropriate housing for women without supports was the subject of many comments:

“Some women aren’t street people, but they’re still homeless. They stay at their mother’s place, then with a friend, and another friend, et cetera. This puts two families under stress living under one roof and it is a very insecure situation to be in.”

“Women in their early twenties are trading sex for a warm place to stay.”

“One woman, for about a year, camped out all over the place and she was an embarrassment to the town. There’s this whole denial, that somehow it’s her fault she is without a home.”

“It’s an embarrassing problem for this community that people are homeless, pushing grocery carts, or begging for change. So let’s put her away somewhere so she won’t be a problem, but had they provided for her in the first place, she wouldn’t have had this problem.”

These women talked about poverty and how it feels to ask for help:

“They thought they didn’t need a food bank here . . . People thought no one would use it in _____. People didn’t know we had it. They used to have it on main street, and



you had to stand outside and wait. You advertise: ‘Hey, I have no food’ . . . They run out of food often. It is humiliating to ask the church for help because your assistance didn’t come in, and they take it to the board and they call you and ask what you need. I have gone to the food bank when I needed milk and bread, but they had none . . . Sometimes it doesn’t meet your need.”

“Social assistance is no life. It ‘s very degrading to use food vouchers. They didn’t treat me well in the grocery stores. Many women leave their marriages with nothing. Social assistance didn’t give me anything for living expenses . . . Everything comes out of the food budget.”

“The voucher system is so dehumanizing and degrading. They could provide cash if they wanted to, but they refuse. This town is as good or as weak as its weakest person and most of the weakest are women and children. Some people barely have what they need, and this is a rich community.”

Social attitudes can be self-perpetuating, as this woman believed:

“It sort of makes you wonder if you’re a young woman in this town and didn’t have much of an education, I guess a really good solution would be to go out there and have a child, go get pregnant and then you’ll qualify for the social safety net. Have two babies and then you’ll get more!”

System Organization and Inflexibility

Women clearly perceive problems with the way the health care system is organized and managed.

“Doctors are too busy”, said one woman, “You have to be almost dying before you can get an appointment at the doctor’s office.” “It takes so long to see the doctor”, said another, “It ‘s a big issue for the women who are working during the day. We need better hours. You take time off from work, it takes money away from the family.” This woman noted: “It’s ‘What can I do for you today?’ The meter is running. So people, even the best organized people, have trouble sneaking in what they need to tell them”.

A number of women wondered if access problems were system-related: “Is it perhaps something in the system that pushes doctors to take so many patients?” queried an older woman. “Is this a billing issue?” asked another, “That is my assumption. I understand, but it is extreme.” A senior woman stated, “The whole system is a little scary”. A physically-disabled woman had this comment:

“I can’t call my doctor any more to get my prescription renewed, I have to make an appointment. I also have to make an appointment if I have a question. I don’t need to see him! I just want to talk to him! . . . The service is degrading. It bothers me. So I gather up my questions before making an appointment, sometimes for several months, then have to wait two hours in the waiting room. It’s especially hard for women who have young children at home or no vehicle. . . Then, when there is in fact a problem, they tell you that you should have come sooner!”

Other women were concerned that physicians’ long hours and high workloads reduced their capacity to spend more time with patients:

“The doctors we have are good and we would like them to stay – if we overwork them they won’t stay.”

“They deserve to hear the positive. What meant the most? Knowing how many patients they take care of, that there is time for us – personable, follow-up in the evening, ‘Do you need anything?’. We phone the ER beforehand – the doctor is always there to meet us. They make an effort. The doctor has to work very long hours.”

At the same time, it was noted that the system often fails to respect the consumer. “My time is valuable to me,” said a farm woman, “I don’t have time to sit 1½ hours when I have an appointment. If I don’t have an appointment I understand, but if I have an appointment, it’s just not right.” A senior woman also expressed resentment: “When I’m seeing the doctor, he gets nine phone calls during my visit. When I leave a message, he never calls me back. In one clinic, if you call and the doctor talks to you, there’s a \$25 charge”. Another senior woman recommended action: “Don’t wait more than 30 minutes in the doctor’s office – go home”.

Continuity of care was also of concern, both in terms of the long-term stability of care and the degree of connectedness afforded individual care. “I’ve seen six physicians in eight years. They all leave,” commented one woman. “I find it really hard when the doctor leaves,” said another, “You build a little bit of a bond and then they are gone. They are here for the experience to get a better job somewhere else. We are a stepping-stone. It is difficult to start over.” An older woman spoke of a young family member suffering from chronic disease: “She has no emotional support, no ideas how to live with a chronic illness. They look on her as a disease and forget that she is a person who has a life. Her life is basically unattended to”. “We have to treat the whole person,” was another comment, “not the body in parts – breast, head, et cetera.” Similarly:

“Nothing has replaced the old family doctor. So now we are lacking, even though we have things we didn’t used to have. Their roles are very specific. We need somebody who is looking at the total person. To help wellness, one must look at the total person.”

Women offered partial explanations:

“Part of the problem is how the system is set up and the other part of the problem is that we look to physicians to give us everything. There’s a public expectation of the physician as god, having all the answers.”

“Women use the family physician – not always the best person to provide that particular service . . . They seek the physician’s help and get into a repetitive cycle of visits without getting the help they need. Sometimes they give up.”

Women wondered if the system could be more flexible around roles, making use of the fact that most health care workers are women. A number referred to the role of nurses: “Nurses are wonderful, very knowledgeable and a great resource . . . They could be used more often to relieve the doctors”; “There are a number of health issues that could be dealt with by a nurse . . . it doesn’t need to be a doctor all the way through”. “I use a masseuse,” said one woman, “Some things don’t really need a doctor.” This young woman talked about the region’s new midwifery program: “My sister had a midwife and it was wonderful. She could call her any time of day and she taught her so much . . . I didn’t have one and I wish I had”.

Many women wished that the health care system could be more responsive. This comment was made by a woman in her mid-twenties, a borderline diabetic who had been referred to a nutritionist: “In _____ they have a dietician come out once a week. I never went, because I would be sitting there with seniors”. A teenager talked about her failed visit to mental health services: “You should be able to go get a mental checkup. It would be great to go to spill your guts. I had to go once – my school made me – but my mom went with me and I refused to talk”.

This teen talked about sex education:

“You get your sex education from magazines. There is no health education in high school. We did have one class, taught by our phys. ed. teacher – he wasn’t even a health nurse, someone who could answer your questions if you asked. Maybe he knew the answers, but then he was a GUY! And then I saw on T.V. where they bring out the banana and then they bring out the condom and they show you how to put it on. And I’m thinking, ‘Well, they never taught me that!’”

A crisis worker had concerns about mental health management:

“A lot of medication prescribed to women for mental health issues is related to domestic violence, because domestic violence isn’t just about hitting. Domestic violence is being at home with six kids and your husband refuses to help and you’re working for minimum wage and you’re losing it because of the stress you’re under . . . What a woman does is she goes to the doctor and says, ‘I’m ready to lose it, this is what’s happening’. The doctor responds, ‘Okay, so you’re not sleeping, so I’ll give you some sleeping pills and here’s some valium for your stress and anxiety disorder’. Then they come to talk to us about domestic violence and we’re trying to assess how they’re functioning, to see if we need to refer them to mental health for clinical depression. We ask, ‘When your doctor gave you these pills, were you referred to a support group to learn about non-medication management of anxiety?’ No, nothing, just the pills, just the prescription. And they wonder about addictions and drug interactions.”

This woman had left an abusive situation:

Barriers To
Gaining Access To
Quality Services

System
Organization
& Inflexibility

“I married an alcoholic. I tried to make it work for 17 years and I had to get out. You see TV ads that tell you to get out and get help. I did, but there is no help.”

A mother spoke of trying to access preventive services for her son, a young man with mental health problems:

“It took me many years to get my son diagnosed . . . and then it was too late. He took responsibility for his dad. His dad planned his own suicide together with my son for a week. He needs anger management help but they won’t give him any until he gets in trouble, unless he pays. He would like help. I could move to Winnipeg and maybe get help for him, but he would lose all his friends.”

Several women talked about the dilemma of gaining urgent access to medical services:

“Doctors’ office appointments are unavailable, so where are we supposed to go? We know that this is not how an emergency room is supposed to be used but we’re caught in the middle. I wouldn’t go to the ER if I had another option.”

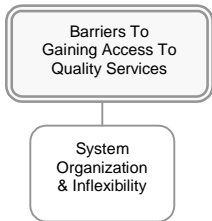
“If they can’t see you in the clinic for three weeks and you think it’s more urgent, they tell you to go to the Emergency Department. If the doctor sees you in the Emergency Department this is costing a whole lot more money for the health care system. The same doctors cover both the clinic and the ER, so somebody is bound to wait.”

“Sometimes we just need reassurance that our child is okay.”

These women, all involved in community service delivery, talked about the limits imposed by rigid service criteria:

“In the old days, I could go out and do an assessment of the situation and say, ‘Okay, folks, Where are you at? What do you need to get back on your feet?’ Now there are restrictions. You pay me a good dollar, let me go out and assess the situation! Treat each case individually! I don’t like a system that treats every situation the same way.”

“In our service delivery we have to think more creatively. We have to think outside of our boxes and how we’ve always done it . . . We’ve all met people that don’t fit into the



system. There are other ways. There needs to be some flexibility. There needs to be some bending. We aren't allowing people to think creatively.”

“We need encouragement and support from management. It takes a little longer to do things in creative ways that actually reach people instead of doing the traditional thing and losing that person, then saying, ‘NEXT’. That way is faster, but then you haven’t served that person and they have fallen through the cracks.”

“Removing the rigidity within the system, fostering creativity – that has to come from the top down.”

“Do we see ourselves cloistered in nice little offices where people come to us to be served when it is convenient to us? Let’s go to them!”

There were also concerns about the ability of the health system itself to communicate, both internally and with allied services:

“Sometimes there are crucial decisions made that should have been communicated between the doctors.”

“I would like to see more communication between surgeons and general practitioners. My doctor never came to see me when I had surgery – I had to fill him in when I went for my check-up. He should get all the reports.”

“Now [my son] is involved with social services. He is heading right back where he started from. It is a revolving door.”

“There’s a lack of understanding about which services each part of the system provides.”

“Doctors, chiropractors, and herbalists should cooperate.”

“We need integration of services in the community, not so separated. We are so fragmented as a society, even in a small community.”

Two women – one a welfare worker, the other an apartment manager – provided an example of cooperation across sectors as they spoke of the informal alliance they formed to help women in adverse social circumstances:

Barriers To
Gaining Access To
Quality Services

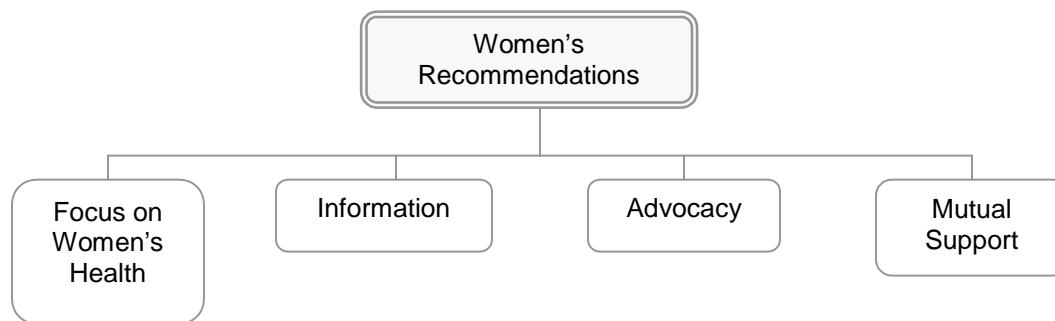
System
Organization
& Inflexibility

“We work together. Out of concern for these women and their need for housing, we formed a partnership. We are constantly trying to wiggle and juggle and try to work things out for people. Our clients are mostly women with children, some long-term disabled, many single women between the ages of 45-60. They don’t have work skills, they often have health problems. They may not actually be disabled, but mentally and emotionally they are going through so much, how can they work? There are very few support systems. Living in a society where being married is the be all and end all, you can imagine what struggles these individuals are going through. We have nothing but heart ache for them.”

Women’s Recommendations: The Role of South Eastman Regional Health Authority in Working with Communities to Improve Women’s Health

When it came to offering the regional health authority advice on ways to work with communities, women had very definite recommendations for strategies most likely to improve their health. Specific programs and services received relatively little attention, with recommendations centering consistently on four broad conceptual areas: focusing on women’s health, information, advocacy, and mutual assistance (Figure 4).

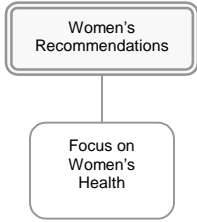
Figure 4. Framework: Women’s Recommendations.



Focus on Women’s Health

The women in this study recommended that the regional health authority and other policy makers focus on women’s health, by listening to the needs expressed by women in the region, by recognizing the social and economic circumstances which affect women’s health, and by acting together to develop more responsive, holistic services in cooperation with other agencies and community groups. They also recommended the continuation of women’s health research in order to fill gaps in existing knowledge stemming from traditional research practices, which have frequently excluded women from study.

Women were very clear in their desire for a focus on “women’s health issues, not just diseases specific to women”. “Women’s health is not well understood,” said one woman. “Women’s lives are fundamentally different from men’s,” said another, “We need to talk



about all of what happens to women that men cannot suffer from, they just don't have the experience." These women summed up common feelings:

"Women's health . . . a lot of it is focused on the cancers – breast cancer and other things. As one of my more outspoken friends says, 'I get so tired of hearing about boobs and butts'."

"I think we have come a long way, we are a little bit better than we used to be. I think men are still number one. When research data are presented, men are always number one and women are always number two."

Addressing women's health issues was seen to require a more holistic approach:

"We need a more wellness-focused delivery of health, rather than illness-focused. There aren't any resources to do that now. Put money behind that. That has to be new money. It is important to do that."

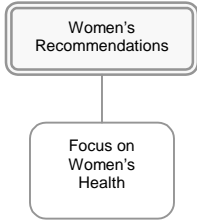
"Health promotion is very important. Work on all the determinants of health. Improving health means improving our communities. Things that are going on right now – enhance them. Involve the educational system. Make it happen from a very young age."

The need to go beyond the health care system and deal with women's vulnerability to adverse social factors was also stressed:

"There are two classes of women, women who have had the opportunity to get an education to be self-reliant and independent and then there's the other class of women who did not have the same opportunities, and we know that their health is going to be different."

"It's about education. Formal education means more money, higher socioeconomic status. If we want to improve women's health, we need to encourage women to assume roles of health research et cetera. It's about empowering women."

"If we don't have ready access to health care, we know that we can compensate somewhat if we have knowledge. But if you don't have knowledge, and a big part of that is socioeconomics, you don't have a choice. This is like putting a ceiling on your potential. All the other determinants will work against you."



“If we can improve the socioeconomic status of women, we can improve their health. Even if they choose to be at home, they have some status.”

“We have women here who live in poverty. We have to alleviate poverty – make housing, social assistance available to women who need it.”

“Do you know how hard it is to get homes for women on low income, especially if they have no children? They remain homeless.”

“When an abused woman can’t find a place to stay, she sometimes returns to the abusive situation.”

“Socioeconomics is big. Women living in poverty. When we see women in the workforce, they are still paid at a lower scale than men. Even in our health care system, men don’t work at the low-end jobs. We need to look at that in our region.”

“Culture is a barrier, preventing women from accessing what they need because they are told what they need. That works hand in hand with socioeconomics. A woman with education will still hold on to some traditional beliefs but also have ideas about things that are healthy for her. But if you combine strong religious beliefs with very poor education and poverty, it is very tricky. It’s a difficult combination.”

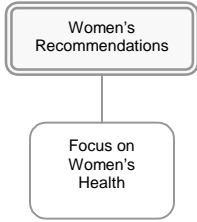
“Transportation is a big problem. People can’t get to the supports and help they need.”

“It’s so far to travel to activities. Especially in winter. You have to be brave.”

“Isolation is a big issue.”

Dealing with women’s health issues was also seen to require working with other delivery sectors:

“Child care. How do you get an education, get a good job, et cetera if there is no child care available? A lot of women have to stay home because they can’t find a job or a daycare. If you do find both, you spend your whole pay cheque on child care. In rural areas there isn’t very much, and they don’t have to give you much notice if they won’t look after your kids anymore. Daycare costs from \$200-500 per month. The after-school program in _____ costs \$550 per month for 2 children. Most of that doesn’t go to the workers’ salaries, and they are mostly women. I don’t know where the money goes – admin, maybe – the most they are going to make is \$12.10 an hour. That isn’t enough money. There are strange requirements for day care workers in this province.



The standards are incredibly high. It's good but ridiculous. The idea of what is "well trained" is wrong. I don't agree."

"We could incorporate day care with the senior centre."

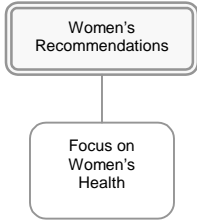
"One of the things we need is . . . income security for women acting as caregivers for family members. I really see this as validating women by providing them with an income and job security while they are caring for their loved ones. It's not just for women, but for men also."

"Services should be accessible . . . Individuals shouldn't have to write letters to council asking for access ramps. There should be policies . . . It's so obvious, just try it, the handicap bathroom – you can get in but you can't close the door, it's not set up for a wheelchair . . . It's accessible, but really it isn't."

"A very important issue for me is to have wheelchair access. The store in _____ does not, so I can't go grocery shopping there. Can the RHA help to get this done?"

"Inter-agency work is very important – domestic violence, legal, police, agency for women, children's aid. They need to work together, knowing what others are doing, and knowing about each other."

A number of women spoke about research directed specifically to women's health. "We need women's health research – researched by women and interpreted by women," stated one participant, "It's one thing to get all the stats, but it's another thing for a woman to interpret it. Especially when it comes to women's diseases like uterine cancer and life experiences, hormone replacement therapy, cardiovascular, mental health." A fellow group member agreed: "Beyond the research, there's the interpretation and application of the data . . . Even if you have ideal stats, you still have to have caring, reflective and meaningful interpretation. Synergy with women working together. Health issues are minimized and dismissed because we are not recognized, which brings us back to the original problem – women's health is not well understood".



There were other comments:

“Look at the alarming rate of hysterectomies, mastectomies, radical hysterectomies, radical mastectomies. If it was a male having organs radically removed, it wouldn’t happen in the same way.”

“Women’s health issues aren’t fully understood, because the research for the last 100 years has been done by men. I’m thinking those hormonal things – peri-menopause, menopause, all those stages in life that we know are hormonally induced and aren’t fully understood, and thus not fully treated.”

“Even the diseases that we both share, like lung cancer, cardiovascular diseases – it’s basically studies by men on men, the data is about men. There may be a fundamental difference in how the genders react to each disease. There is a difference.”

Above all, women expressed the need to be heard:

“We want to be understood about our health problems.”

“Listen to us.”

“Listen to what women have to say.”

“It’s nice to have this forum where we can talk just about women’s health.”

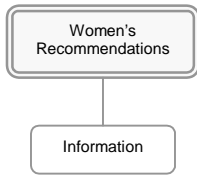
Information

The women in this study repeatedly identified the need for more information on women’s health concerns and had several recommendations for innovative ways to make that information more accessible. They recommended that women’s health information and lists of services and support groups be provided in public forums, a variety of media, and through distribution to schools, stores, agencies, and other places frequented by women. They also recommended that women have the opportunity to ask questions and receive help in finding and interpreting the information they need to deal with particular health issues and concerns.

“We would be a lot healthier as a community group if we were more informed.”

“Information . . . to be guided . . . to know where to start. Getting help is like a gift.”

“When the doctor gives us choices, he must first provide information to allow us to make



wise decisions.” These statements reflected the beliefs of women across the region.

Women had many recommendations for ways to communicate information about health, the health care system, and available services. The need for multiple mechanisms was apparent:

“Community forums, like the one on mental health. These let us know which services are available, how to access them, and where the gaps are; for example, mental health services for adolescents.”

“Discussion groups and workshops on women’s health topics.”

“Workshops and information sessions.”

“Educational forums.”

“Information centres.”

“A *Health Corner* in every community.”

“Health information in clinics, libraries, local community papers.”

“Put information in pharmacies and grocery stores.”

“More information in the newspaper.”

“Spots on local radio.”

“A coordinator of information.”

“Health videos in lending libraries.”

“Information in church bulletins.”

“TV ads.”

“We need a hot line . . . a line where people can start calling.”

“A medical info line.”

“Give me an information package, and I can use it the way I would like to, read on my own.”

“Put information on occupational health at the employment office.”

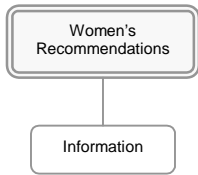
“Education on what is and is not helpful information on the internet.”

“Education on women’s health in junior high and high school.”

“Theatre to teach women to deal with their issues.”

“A health services directory.”

“The phone book is not good enough. A more detailed directory is needed.”



“We need a list of support groups and where to contact them.”

“Send out a newsletter. Put in there women’s issues, concerns that are coming from women. Women would read it.”

“The best way to communicate is word-of-mouth networks”.

Women were mindful, however, of the many obstacles to be overcome in sharing information effectively:

“We have to get information out to where women go – school, grocery stores (maybe in the bags?), churches.”

“Information has to include phone numbers and names.”

“Some parents don’t want things to be talked about in school.”

“Workshops for professionals should teach them to examine their biases and see how damaging it is to impose their personal beliefs on clients.”

“It has to be a reputable person coming to do the presentation. Not doing one thing and saying something else. It should be a person from the outside. A message coming from a person they know isn’t the same.”

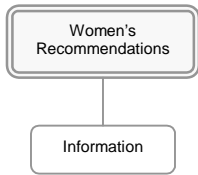
“Pamphlets are good but, when you look at socio-economics, do women have the skills to read them? They often don’t have the skill to read for comprehension.”

“There’s misinformation. And health professionals have only general knowledge, not specific. Get the experts to come.”

In particular, there was a strong sense that many women require not just information but substantial help in putting that information to use to better their own health. This woman pointed out, “Women need help. Even if you tell them where help is, the chances of them getting to it are limited, not only by transportation, inflexible hours, children, social stigma, and lack of confidentiality but by general attitudes.” Others agreed:

“You have to be informed but you first have to be given permission. So many women don’t even know that they are entitled to make a choice.”

“First you support, then you inform . . . To give women piles of information first is to overwhelm them and gives a message that you don’t care about them as a person.”



“We are talking about relational involvement – valuing differently. Instead of just giving this woman information, you join with her. And that’s what women do well.”

“We have to go beyond the posters.”

Advocacy

The women in this study called for community action to recognize women’s strengths and needs and work actively to promote and support women’s health and well-being. In recommending advocacy for women’s health, many women envisioned a multi-faceted process, strengthening advocacy mechanisms within communities of women as well as within the regional health authority and other service systems; others saw a formalized process, with the establishment of a women’s advocacy centre. Women acknowledged the many challenges involved in coordinating advocacy for women’s health but viewed women’s advocacy as a key instrument in improving the health of the entire community.

“Without that strong voice of advocacy, we are still the passive recipients – waiting for the research, waiting for the response – and we need to be more active.” This woman’s call for advocacy was echoed by many others:

“Women have the right to ask questions.”

“Women need to take health into their own hands. “

“It would be really nice to have a women’s advocacy group here, like in Winnipeg. We need someone to advocate for women – ‘Were you happy with the doctor’s treatment of you? If not, maybe you need to go back and ask these kinds of questions’.”

“We need a women’s advocacy office.”

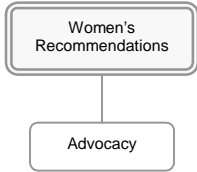
“It’s up to women to raise consciousness – ask for accountability.”

“Cash in on your strength, do it well for others.”

“Our need to help and caregive . . . legitimize it.”

“If we could all mentor or advocate for just one other women, like a sisterhood, and we say ‘I only ask that you do this for one other woman’, it would be a chain.”

“This whole issue of advocacy. It’s huge. It is totally huge. The average woman does not know where to turn.”



“I think I have to say right now that everywhere I turn I feel that women need a voice.”

It was perceived that coordinating advocacy for women’s health would not be an easy task:

“Women’s advocacy. You would reach out to some, but maybe not to the hard to reach people with high needs.”

“How are we going to get women to ask questions?”

“The women who need help the most – always, traditionally, evermore, still to this day – are the weakest, the most needy. They are always the hardest to reach.”

“In this community you might find yourself knocking on six levels of brick walls if you wanted to start a woman’s advocacy centre. Traditional religion would find that pretty threatening.”

“Before the huge changes came, nurses, certainly in the acute care hospital, and public health nurses, had more time to be advocates than they do now. Now, and certainly in hospitals, they have very little time for advocacy.”

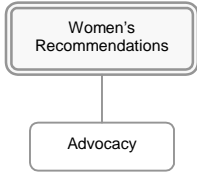
“We’ve changed. We’ve lost the level of advocacy that the nurses and family doctor used to do. It’s gone as far as I can see. I don’t think it’s in their job descriptions now. If you would ask them, I doubt that one out of ten would say that it was part of their job.”

“Our own staff need to have more knowledge about services that are available and how to advocate for others. We have to teach staff how to teach consumers to find help when they need it.”

“We need more of the embodiment of health and more mentoring and role modeling by healthy women. Oprah is a model. Malcolm’s mother in *Malcolm in the Middle* – she’s a good role model, she says it like it is and doesn’t take any bullshit from anyone.”

“It takes a fair amount of mental and physical energy to advocate and be determined about health.”

Nevertheless, advocacy was seen as a key instrument in furthering health, not only of women but of the community as a whole:



“It has a ripple effect that is enormous . . . It can have profound effects in creating whole, strong communities. And strong communities can become models, and we can have epi-centres of health.”

“For the males who are the power brokers, those who make the decisions, they need to understand that if women are helped to being healthier, the men will be more healthy too.”

Mutual Support

The women in this study identified a very real need for communities of women to begin building on their collaborative strengths to forge linkages, share information, and support one another. They made a number of recommendations for potential support systems, including informal phoning networks, a formal women’s health network, visiting programs, and support groups, particularly in the areas of mental health and cancer.

Women across all communities talked about the need to help each other and draw strength from the company of other women:

“Women can help women.”

“We have to look after each other.”

“Women have a more natural tendency for collaboration. Whoever wants to be part of our team is welcome, and that’s a strength.”

“Binding together . . . My strength will strengthen you.”

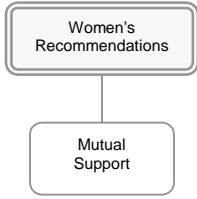
Women spoke often of the need to feel connected. “Women need networks to live within, they need to feel connected to each other,” one woman noted, “We need many different networks, for different women and different situations.” There was a strong sense of needing to share problems with other women who understand, as these comments demonstrate:

“There’s power in getting together with people who have the same problems.”

“A group of us, all the same thing in common.”

“Someone from the breast cancer support group came to visit me after my surgery.

This is a good example of women helping women.” “You need to talk to someone with



the same problem. It's inexpensive, it just needs to be organized. It relieves stress that can cause other things."

Beyond the need for problem-sharing was the desire for simple camaraderie around shared circumstances and life experiences:

"I wish we could have francophone support groups in our communities."

"I would like a support group for when you get home with your baby, so you also meet people in the same situation."

"Playing cards and getting together – it's good for your mind."

"Sometimes seniors need someone to talk to rather than a physician office visit."

"Something in an informal setting. It would be nice to sit around and chat."

"My daughter goes to twins and triplets group in the city."

"Our prenatal group has continued to get together."

The need to reach out and be heard was also frequently expressed:

"I feel that I am the only woman going through this."

"Somewhere, someone to call when we don't know where to go for help."

"It would be nice to receive or to be able to make just a phone call when we are going through a tough time."

"Most people don't understand mental health. Even if you read it, you have to experience it. My husband doesn't understand it, he just knows how it affects me."

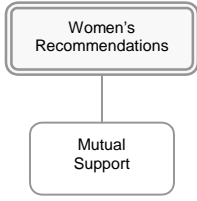
"Because you're at home, the problems are all yours – your kids, your husband. If you have problems, there's nobody there for you. We should have a group once a month to blow steam."

"It's really good to have these groups, to be able to talk."

"It feels good to dump on someone."

"You can't download on friends all the time – you need to talk though, family and friends can't take it all the time."

A number of women envisioned systems for supporting each other and sharing information about health. "We should have health parties where we get information,



without buying anything,” suggested one woman. Another woman proposed “a women phoning tree, where we share information about a course, call each other – recruiting. A contact person in each community . . . recruit people from your community”. “Maybe part of our role should be being instigators of groups,” said a health provider, “foster them and help them get started – it seems like a very powerful tool.” There were other ideas:

“Women forming information networks to keep each other informed.”

“A South East women’s health network.”

“Have different support groups in different areas on different topics – mental health, addictions, gambling.”

“Set up support groups closer to home.”

“Cancer support groups for families.”

“Support groups for women who are depressed.”

“Supporting each other over the phone, and communicating – sharing information.”

“Visitors for the elderly.”

“Women helping women.”

“Health care can’t solve everything, we need to work together.”

“Let’s do something about untying those ropes. This is ridiculous! Let’s have some common sense and do something about this!”

Discussion

Whether as users or facilitators, care providers or family managers, women exert great influence on the health of communities and the way community health care systems are used. In planning for better health and in fashioning services to meet community needs, administrators do well to heed women's experiences and to respect their ideas and opinions.

In this study, a rural Manitoba regional health authority sought women's perspectives on health and health services in an extensive consultation process that involved women from diverse backgrounds, experiences, age groups, and geographic areas. Clearly, the health issues uppermost in women's minds are the many stumbling blocks they encounter when dealing with the health care system, whether in-region or elsewhere. The constancy of themes and the compelling nature of women's words highlight how difficult the health system often makes it to reap the full benefits of services. As organizations begin to place more emphasis on providing quality health services, this study offers a number of starting points for further inquiry and reminds the health system that the final word on quality ultimately rests with consumers.

This research has considerable significance because of its focus on gender as a factor determining health and health care. The findings underscore the distinction between *gender*, the different socially and culturally defined roles, characteristics, and positions within society of men and women, and *sex*, the biological differences between men and women.^{11,12} Although relatively little research to date has looked at gender as a health determinant, it has been recognized for some time that diseases and conditions which affect both men and women may affect men and women in different ways.¹¹ Heart and cancer research, for example, show that men and women differ in terms of symptoms, diagnosis, treatment, and rehabilitation needs, requiring different approaches to care. Gender has an impact on many risk behaviours associated with heart and lung disease, such as exercise, diet, stress, and smoking. In the area of mental health, gender influences biological factors to produce different effects – increased depression in women, increased anti-social behaviour in men, more eating disorders in women. In

other words, gender interacts with sex differences to create health situations that are different for men and women, both as individuals and as groups.¹²

The influence of gender on health becomes strikingly evident as we read the statements and stories of South Eastman women. Gender clearly determines the processes women value most when it comes to health – taking responsibility, communicating with the health system, and gaining system access – and gender plays a very significant role in determining the factors women identify as barriers to health and health care. Directly and indirectly, socio-cultural environments shape women's views on health and create particular circumstances that limit access to health services and diminish the effectiveness of the delivery system. Efforts to lower these barriers are important, not simply because they stand in the way of women's health but because the societal roles assigned to women mean that factors affecting the health of women also govern the health of families and communities.¹²

An equally important aspect of the study is the insight it provides on interactions between gender and other determinants of health. The women interviewed represent such a broad cross-section of South Eastman society that, in their descriptions of barriers, they unconsciously reveal how the familiar determinants – age, culture, income, education, and employment – exert their influences on health, illness, disability, health-seeking behaviours, and access to health services. Women provide insight, too, on the impact of violence, a determinant often overlooked by the health research community.¹² Most importantly, however, we read in the comments and stories how the barriers that women face on socio-cultural grounds become more formidable and fixed as the determinant scale is descended, from high income to low income, from well-educated to poorly-educated, from cultural majority to cultural minority, and so on.

A notable lesson from the study, therefore, is that women do not represent a single population health group, any more than men do, or children, or seniors. Women cut across and encompass all population health groups, representing a continuum of health, illness, strengths, and risk factors.¹² Based primarily on quantitative data, South

Eastman regional health authority has already identified women as one of the region's priority vulnerable population groups. Information from this qualitative research now offers firm direction to health planners, not only around improving the overall quality of services and addressing factors that impede women's health, but in acknowledging that a single approach to service delivery will not suffice for all women and in designing strategies accordingly.

The next challenge for the regional health authority, having commissioned this study, will be to consider how the recommendations of South Eastman women might be translated into operational realities. Women tend to see better health deriving largely from enhanced mechanisms of self-help – advocacy and mutual support. In their recommendations, women ask relatively little of the health system in terms of change – a focus away from disease towards health and improved information-sharing, around both health and health services. It is to be hoped that, despite the current environment of fiscal restraint, ways can be found to fulfill women's hopes for change and meet their underlying needs – for greater respect, for more accessible, holistic services, for better communications with health care providers, and for information and assistance in finding the mutual support and services they require to deal with health problems.

Policy Recommendations

The purpose of the study was to seek guidance from women, based on their knowledge, opinions, and life experiences, on how to improve women's health and health services within a rural Manitoba health jurisdiction. The primary intent of the research, therefore, was to obtain information to direct policy-making and planning by the local regional health authority and other community groups and agencies. The broad implications of the findings with respect to gender-based policy issues are of general interest and applicability to all health and related organizations. The following areas of significance, together with general policy recommendations, have therefore been highlighted.

Acknowledging gender as a determinant of health. Gender is a key health determinant. While a number of diseases have biological bases, affecting men and women uniquely, many other major health problems, such as coronary heart disease, chronic lung disease, and mental illness, differ markedly for men and women, not only in incidence and prevalence but in severity, symptoms, diagnosis, and treatment. These dissimilarities are more complex than simple biology; they reflect the role of gender – the different socially and culturally defined roles, characteristics, and positions within society traditionally assigned to women and men. Gender influences lifestyle and shapes social behaviours, so that, as population groups, men and women tend to face different health risks and respond to prevention and intervention in vastly different ways. Gender interacts with the major socioeconomic determinants of health, influencing not only education, employment, and income – factors which govern access to the basic necessities of life and health – but also the knowledge, attitudes, and health-seeking behaviours that can buffer adverse socioeconomic circumstances for individuals and families. As the women in this study have so clearly described, gender also influences health services, affecting decisions and choices, access, satisfaction, and quality. Gender is therefore a very powerful determinant of health, affecting virtually all other major determinants to create different health situations for men and women.

Recommendations:

- **Incorporate gender-based analysis as a routine component of decision-making.** This means not only ensuring that data for evidence-based decision-making are collected and analyzed in sex-disaggregated form, where available, but examining policy and planning decisions, where appropriate, with an appreciation of gender variations to assess the potential for differential impacts on women and men.
- **Promote awareness and education on the role of gender in determining health.** Awareness and education should be targeted both to the public and to health personnel, at all levels within the system. Teaching should relate to the social dynamics of gender and to differential impacts on risks to health and responses to prevention and intervention. A holistic approach should be taken,

considering health in the life context rather than focusing on specific diseases and conditions.

Acknowledging gender as a determinant of health services. Gender influences health services at very fundamental levels. By shaping values, attitudes, and behaviours, gender determines health choices and decisions, affecting the importance people assign to health, how they seek help, interpret symptoms, and follow advice, and the types of treatment and support that offer relief. Gender is also a very significant factor in communication. Men and women generally have very different styles of giving and receiving information and different expectations and interpretations of the information exchange. As the study underlines, the health care setting is highly vulnerable to communication breakdown and gender disparities tend to aggravate problems, heighten anxiety, impede interaction, and diminish satisfaction. In addition, just as sociocultural factors define gender, so do they shape social groupings, within which people espouse common beliefs, attitudes, and codes of conduct. Virtually all social groups, however, assign standards of behaviour based on gender so that, while classism and social prejudices tend to be factors of everyday life, they may have very different effects on men and women. Moreover, as the study describes, the intrusion of intolerant and judgmental attitudes in the health care setting can jeopardize not only access and satisfaction but the quality and outcomes of health services provided.

Recommendations:

- **Strengthen the processes that women value.** Women place particular value on key processes that enhance access to health and health services, namely taking individual responsibility for health, communicating successfully with health staff, and gaining entry to the health system and access to necessary services. Education and resources are required to help women develop and enhance skills around these processes and to equip staff with the appropriate knowledge and tools to give meaningful support to all health care consumers.
- **Acknowledge women's priorities.** This means respecting women's collective wisdom and life experiences and acting on their priorities and suggestions.

Policy-making and planning should build on women's recommendations by working with communities to facilitate networking, mutual support systems, and advocacy mechanisms for women's health and health issues, as well as fostering effective communication and information exchange between health providers and consumers.

- **Involve consumers in health planning.** Consumer participation in planning should be part of the health system's quality management process. This means involving consumers at various stages of program and service planning, including needs assessment, design, implementation, and evaluation. The approach enables the health system to benefit from consumer knowledge and experience in identifying and meeting community health needs, monitoring the appropriateness of services, assessing policy and planning decisions from key perspectives, including that of gender, and measuring effects in terms of health outcomes and consumer satisfaction.
- **Promote and support gender-oriented health services research.** There is very little information available to guide the health system in understanding the impacts of gender on health services, the interactions between gender and other determinants, and the effectiveness of interventions directed to improving health among men and women. In addition, each organization responsible for health service delivery is unique in terms of its structure and composition and the characteristics of the population served. Gender-oriented research should therefore be prioritized as a basic prerequisite to planning health services for women and for men, keeping in mind that population-specific research provides the best guide to organizational decision-making.
- **Promote awareness and education on the role of gender in determining health services.** Awareness and education should be targeted to the public and to health personnel at all levels throughout the system. Teaching should relate to the ways in which gender can impact both the delivery and receipt of health services, focusing on health behaviours, effective and sensitive communication, power relations, and the impacts of personal values and belief systems on

interactions in health settings. Tools and resources should be developed to assist in the educational process.

Recognizing population diversity. Because gender spans the societal spectrum, patterns of health among men and women are extremely diverse, reflecting the complex inter-relationships of gender with other factors influencing health. Needs for health services are equally varied, since the major determinants of health also determine many aspects of health care. Within gender groups, gradients in age and socioeconomic circumstances – particularly education, income, and employment – produce different levels of health knowledge, understanding, motivation, and receptivity. At the same time, age and socioeconomics also define key health service characteristics, including appropriateness, distribution, intensity, and accessibility. A blanket approach to women’s health, or men’s, cannot reach whole populations and tends to exclude the least advantaged members of society.

Recommendation:

- **Maintain a population-based, evidence-based approach to health policy-making and planning.** This approach, by taking into account population diversity with respect to life circumstances and life experiences, enables the tailoring of health services to address the very wide range of health and health care needs within gender groups.

Addressing system problems. Despite many changes in recent years, health services generally remain organized along traditional lines and in accordance with historic funding patterns. As the current research highlights, methods of organizing and administering health care can very effectively limit access, setting barriers which, while not gender-specific, disproportionately affect high users of services. The women in this study cited specific examples of system problems, including a lack of language-appropriate services, inflexible points of access to the health system, and poor inter-provider communication. While these observations may not be generally relevant, they suggest that current configurations of health service delivery may fail to satisfy client

expectations of service effectiveness and/or quality and should, at least, be open to question.

Recommendation:

- **Examine enhanced and alternative methods of service provision.** The effectiveness and quality of local programs and services should be subject to review incorporating consumer perspectives, and the cost-effectiveness of enhanced/alternative service models explored.

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