The Challenges of Change
The Midlife Health Needs of Women with Disabilities

By Marina Morrow with the Midlife Health Needs of Women with Disabilities Advisory Committee

Report available in alternate formats

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By Marina Morrow with the Midlife Health Needs of Women with Disabilities Advisory Committee

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DAWN Canada Research Guidelines

1. The need for research is determined by the disabled women’s community.

2. Research must always benefit women with disabilities.

3. Research must be done by members of the disabled women’s community because members:
   
   a. Know the issues and priorities of the community;
   
   b. Understand the day-to-day reality of women who are disabled;
   
   c. Understand the social and political dynamics of the community;
   
   d. Can analyze data within the framework of these dynamics.

4. Action resulting from the research must be directed toward making positive change for women with disabilities.

5. Research participants will be given the results of the research in an accessible format if they so desire.
Dedication

By Joan Meister

We would like to dedicate this report to Shirley Masuda, whose work on this project and in the service of the lives of women with disabilities has been invaluable.

Shirley, who was deaf in one ear and hearing impaired in the other, was an activist in the Ottawa disability community before moving to Vancouver. While working for the British Columbia Coalition of People with Disabilities, she became involved with DAWN Canada: DisAbled Women’s Network, becoming their senior researcher and formulating what were adopted as DAWN Canada’s Research Guidelines. Shirley went on to help organize the DisAbled Women’s Network of British Columbia (now known as Pacific DAWN).

In her work with DAWN, Shirley pioneered research on issues of concern to women with disabilities in Canada and internationally, particularly in the areas of violence and suicide. Shirley had an ongoing interest in helping women who were survivors of childhood sexual abuse, rape and domestic violence, volunteering in rape crisis centres and teaching self-defence courses. Working collaboratively with other leaders in the women’s movement, Shirley helped to develop both the “Rape Shield” and “Anti-Stalking” laws.

Shirley designed and carried out a project with the support of the British Columbia Centre of Excellence for Women’s Health entitled, Women with Disabilities: We Know What We Need to Be Healthy! This led to further collaboration between Pacific DAWN and the British Columbia Centre of Excellence for Women’s Health, which has resulted in this current project. Shirley played a significant role in the present project as the senior researcher who guided the development of the research design and carried out all of the interviews with the women. Shirley died of cancer on May 21, 2000 before she could begin to write up her findings. Even as her illness advanced, Shirley remained firmly committed to this project and to the lives of the women it might influence.
Shirley was a mother of three daughters and grandmother of two grandsons. A vegetarian who shared her life with many important creatures, she often wore a button which read, “Love animals, don’t eat them.” In recent years, she developed a private, accessible counselling, hypnotherapy and craniosacral physiotherapy practice. Her contributions to the women’s movement are huge and she will be greatly missed by women across Canada.
Acknowledgements

This research was made possible through the collaboration of Pacific DAWN and the British Columbia Centre of Excellence for Women’s Health. This project is funded by the Health Transition Fund, Health Canada, and is co-sponsored by Pacific DAWN and the British Columbia Centre of Excellence for Women’s Health. This project is also a part of the Women’s Health in Midlife Project (WHIM), a provincial initiative designed to help women make informed decisions about managing key midlife health issues through health education and community action.

Many people gave of their time and knowledge in the development of this project. Shirley Masuda was the original researcher on this project, and we would like to acknowledge the key role she played in designing and carrying out the research. We would like to recognize the excellent leadership of Joan Meister as the Chair of the Advisory Committee and the dedication of Celeste Wincapaw who worked to co-ordinate the project. Special thanks to Sue Mills who spent many hours developing the analysis tool and analyzing the emerging data.

Other members of the Advisory Committee provided guidance on specific aspects of the project. Barb Goode acted as an advocate for women with disabilities and educated the research team about how best to access women. Barb, along with Sally Thorne, Joan Meister, Sue Mills and Kim Vlchek provided thoughtful comments on drafts of the paper. Karin More provided critical support to the advisory committee, recording minutes and doing data entry. Christine Zarowski, Gail Roberts and Kathy Marshall all lent support to the project at various points in its development.

We would also like to thank Lorraine Greaves for her comments on drafts of this paper, our editor, Janet Money, Robyn Fadden for her copy editing and Michelle Sotto for her graphic design work.

Finally, we would like to acknowledge all of the women who agreed to be interviewed for this project. Their generosity and sharing have assisted us in better understanding the lives of women with disabilities at midlife.
Executive Summary

This study highlights the interconnections between menopause, disability and aging. Interviews were conducted with thirty-nine women with physical disabilities and chronic illnesses. Twelve interviews were conducted with women with developmental disabilities and their caregivers. These interviews probed the women’s experiences and thoughts about the relationship between menopause, midlife, disability and aging. We asked about their personal health challenges, as well as their views on the information available through the health care system regarding midlife and disability.

The data illustrates how difficult it is to distinguish the differential impacts of menopause, aging and the effects of a particular disability. The women noted this, and clearly identified the need for more comprehensive information that would assist them in understanding their particular disability and its impact on menopause. In addition, the lives of women with disabilities are often marked by poverty, experiences of violence, and social discrimination. In this context, significant midlife events, such as divorce, shifts in caregiving roles, and the death of loved ones, contribute more complexity to the experience of midlife for women with disabilities.

A key finding of this study is the identification of methodological issues which must be addressed in subsequent research. For example, clarifying the operational definition of “disability” and the issues connected to including women with developmental disabilities in research are two issues of importance. Attention to these methodological issues will yield information helpful in addressing both gaps in health care practitioner knowledge about disability, aging and menopause, as well as in designing information materials for women themselves.

Current approaches to defining disability reduce our understanding of disabilities as a continuum of abilities, often connected to women’s own self-definations and integrally linked to changing social and economic understandings of disability. A woman’s self-definition affects how she will frame her experiences of menopause and midlife and is an important factor in the kinds of information and support she will require.
Women with disabilities are part of our aging female population; however, it seems very little is known about the specific experiences and concerns of the relevant midlife issues.

Distinctions between different types of disability and their age of onset are important factors in understanding the specific physical and emotional challenges women may experience at menopause. More research is required to support the development of appropriate educational and health promotion materials for women with disabilities and the health care professionals who assist them.
Context

A. Background and Rationale

In the past decade there has been an information explosion in the area of aging and menopause (e.g., Love, 1997; Barbach, 1993; Reichman, 1996). This growth in information reflects demographic changes towards an increasingly older population, the majority of whom are women (Norland, 1994). This trend has meant more attention in the scientific literature toward understanding the physiological and emotional changes which accompany menopause. At the same time there have been challenges to traditional scientific understandings of menopause (e.g., Prior, 1998) and the promotion of naturopathic remedies to augment or replace traditional treatment responses such as hysterectomies and hormone replacement therapy (BC Women’s Hospital and Health Centre, 1999). Further, researchers have been urged to take a more contextual approach and to study the social and life changes that women often experience around the time of menopause (e.g., children leaving the home, divorce, increased poverty, the death of loved ones, increased caregiving responsibilities as parents age). The interactions between these common life events, aging, perimenopause and menopause have become a focus of research. This has resulted in the use of the term “midlife” to better encompass the wide range of experiences women have during this phase of their lives.

The women’s health movement has been influential in bringing the concerns and needs of women at midlife, especially during menopause, into public consciousness and discussion. The women’s health movement has spawned popular education tools which are designed to empower women to learn about their health needs, challenge the medicalization of women’s bodies, and take control of their own health (e.g., Boston Women’s Health Book Collective, 1992). This movement has also resulted in a positive framing of midlife as a time when women “change for the better” and potentially rediscover themselves (e.g., Reitz, 1982; Porcino, 1983; BC Women’s Hospital and Health Centre, 1999). These developments are at their strongest when collaborations between women’s health advocates and feminist health professionals...
have resulted in the consideration of both the social and physical determinants of women’s health at midlife. There is no doubt that these efforts have been successful in informing a certain population of women about midlife changes and health care options during perimenopause and menopause.

Approaches which emphasize empowerment and women’s choices are often inadequate for women with disabilities, who may face very different challenges at midlife than their non-disabled counterparts. These challenges are often directly related to struggles around gaining or maintaining autonomy and self-determination in situations where some amount of dependency on others is necessary. Women with developmental or psychiatric disabilities may spend long periods of time in institutional or group home settings where they have little control over their lives. In relation to reproductive health, decisions are often made by physicians and family members. For example, women with developmental disabilities have often been sterilized without their consent (Asch & Fine, 1988).

Poverty is both a cause of disability (Lohr, Kamberg, Keeler, Goldberg, Calabro & Brooks, 1987) and a result of it. For example, conditions of poverty make it difficult for people to maintain good health and can lead to disabling conditions. On the other hand, people with disabilities experience barriers to educational and employment opportunities, which often forces them to live in poverty (Chirokos & Nickel, 1986; Williams, 1991). Women are at a higher risk for poverty than men are; this risk increases as women age (Statistics Canada, 1994-95; Funkhouser & Moser, 1990) and is more pronounced for women with disabilities (Statistics Canada, 1991; Statistics Canada, 1996-97), First Nations women and immigrant women. The combination of poor health, lower levels of education, communication barriers and fewer resources limit the access of women with disabilities to health services and health information, including information related to menopause and midlife health. This is particularly true for women with developmental and/or psychiatric disabilities who are even more stigmatized and who often have less access to resources than those with physical disabilities.

Women with disabilities also disproportionately experience sexual and physical violence (Doucette, 1986; Waxman, 1991; Masuda, 1992); some of this abuse occurs in institutional settings. These experiences have an effect on women’s ability to trust health care providers and
recognition of the ways in which women with developmental disabilities have been marginalized, an attempt was made at each step of the process to ensure that the design of the research would facilitate participation of this group of women.

This project was designed to better understand the midlife experiences of women with disabilities. Four questions guided the research:

- What are the needs of women in midlife with disabilities?
- Do midlife changes have an effect on a woman’s disability(ies)?
- Does a woman’s disability(ies) have an effect on her midlife changes?
- Are there different midlife needs for women with different types of disabilities?
Methodology

“The social experience of living with chronic illness and disability is neither gender nor context neutral (Thorne, McCormick & Carty, 1997, p. 2).”

It has been noted that although there has been a great deal written in the area of women’s health and disability respectively, surprisingly little cross-fertilization has occurred (Thorne et al., 1997). This is because disability studies continue to be dominated by male researchers and guided by traditional research paradigms which do not take into account how factors such as gender, ethnicity and socioeconomic circumstance influence social experiences. As Thorne et al. state:

“…chronic illness and disability studies have for the most part taken on a posture of gender, race and social class neutrality to the extent that they are not easily identified as arenas in which social justice or gender inequity are at issue (1997, p. 2).”

Priorities for research on disability do not reflect the actual incidence of disabilities within the population (Saunders, 1985); rather, research agendas have often been set according to the needs and concerns of dominant populations (Thorne et al., 1997). Traditional science methodologies using “convenient” populations (e.g., war veterans) have given us the bulk of the information we currently have with respect to disability. That men and women might experience disability differently because they are differently socially situated has not been addressed comprehensively in the literature to date.

This is evidenced in the focus in the literature on conditions that mostly affect men (spinal cord injuries) and by the fact that conditions primarily affecting women (e.g., chronic fatigue syndrome and fibromyalgia) are sometimes even questioned as to their very existence (Thorne et al., 1997). Further, since resources (both in terms of research money and biomedical technical developments) are guided by these priorities, women’s health is severely affected.

Feminist writing and theory has, with some notable exceptions (e.g., Hillyer, 1993; Wendell, 1992), neglected to incorporate the experiences...
Several significant methodological challenges were identified at the outset.

of women with disabilities and to listen to these experiences for how they might expand our theoretical understanding of the body, identity and critiques of the medical model (Wendell, 1996; Asch & Fine, 1988; Thorne et al., 1997). Thorne et al. (1997) suggest that potentially conflicting agendas between non-disabled feminists and feminists who have a disability may, in part, account for this neglect. The impact of this is wide-ranging, especially when applied to developments in women’s health. In relation to this study, for example, there is a dearth of information about the midlife and menopausal needs of women with disabilities, in particular, research centred on the knowledge and experience of women.

The research that has been done tends to focus primarily on the needs of women with mobility disabilities and studies which document the impact of specific therapies on specific conditions (e.g., Collins, Rosano, Jiang, Lindsay, Sarrel & Poole-Wilson, 1993; Lufkin, Wehner & O’Fallun, 1992; Gill, 1996). Generally, these studies do not take a broader contextual approach that includes an analysis of the impact of social and life changes on women with disabilities at midlife.

A. Putting Women with Disabilities at the Centre

The design for this particular study was arrived at through a collaborative process which engaged a diverse group of women in discussion about how best to assess the midlife and menopausal concerns of women with disabilities. The advisory committee was comprised both of women who identified as having a disability and those who did not. The committee had representation from both academics and community-based disability activists. An active process of negotiation was therefore necessary to reconcile sometimes disparate positions. For example, definitions of disability that have arisen out of particular political strategies sometimes conflicted with those most suited to research. It was recognized early on that there was inadequate support within the literature to guide such a process, and that others might appreciate an awareness of the nature of the issues and the challenges that were faced in applying collective knowledge to this complex field.

Several significant methodological challenges were identified at the outset. These are mentioned here in their specific relationships to research tool design and are elaborated upon later in section IV.
B. Defining Disability

One of the most challenging aspects of this research was to find a way to recognize the complexities associated with defining disability, while at the same time come up with information that might inform our understanding of how specific physical and emotional conditions affect a woman’s experience of midlife. The term disability is variously used to describe a loss of functional capacity or activity and the particular social discrimination that people face as a result of impairment. In addition, there is disagreement about whether or not to describe chronic illnesses as disabilities. For example, most disability statistics do not include people who have chronic illnesses. However, as evidenced by our study, some people with chronic illnesses consider them disabling and describe themselves as disabled. A woman’s own definition of this may depend on a number of different factors, including whether or not her illness is visible and/or the degree to which it restricts her life, and whether or not she is politically engaged with the disabled consumer movement.

The definition that DAWN uses as a matter of its standard research policy and practice is that of self-identification and self-definition. This policy is meant to be as inclusive as possible, but the advisory committee recognized that this definition may also inherently exclude certain groups of women on a systematic basis. For example, women with developmental disabilities may or may not self-define as having a disability. Although we did not solicit any chronically ill women who do not identify as disabled, we did actively solicit women with developmental disabilities, regardless of how they labeled themselves. This reflected an explicit awareness that the voices of women with developmental disabilities are rarely heard in disability research, and our belief that special efforts to include them were justifiable. Therefore, our mutual objectives of being inclusive and respectful of individual women’s perceptions of their own situations were sometimes in conflict with each other and compromises had to be agreed on.

Further, a woman’s self-identity is not static and not reducible to her disability. A woman may identify as disabled for the purposes of accessing services and as non-disabled for the purposes of normalizing her life and managing relationships. A woman may have more than one disability at a time and the nature of her disability may change over her life span. Women with the same disability may not necessarily classify it in the same functional category.
For example, a woman with fibromyalgia may consider it a hidden disability, a mobility disability and/or a psychiatric disability.

A woman’s self-definition also ultimately affects how she will frame her experiences of menopause and midlife. For example, whether or not a woman attributes certain emotional and physical changes to her disability or to menopause may depend on her self-definition.

In our study, we found it most useful to make a distinction between the medical categories of disability and illness and how these are socially constructed. We use the term disability in its broader social sense to highlight the interaction between impairment and access to financial and social resources.

Operationalizing this in our study was difficult. In recognition of the fact that women may have more than one disability at any given time, we first asked women to select as many categories of functional disability that they felt applied to their situation. We then asked women to identify what their primary disability was. Interestingly, women generally defined their disability in terms of impairment or in terms of a medical category of chronic illness. All of this information was coded; however, the researchers also made decisions about which functional category best applied to each woman, based on her self-report and also on which disability appeared to have had the greatest impact on her life.

The youngest age group (35-45) had the largest percentage of persons with a mobility disability (4/9). The age groups 46-55 and 56-65

<table>
<thead>
<tr>
<th>Women’s Primary and Secondary Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Disability</strong></td>
</tr>
<tr>
<td>Hidden</td>
</tr>
<tr>
<td>Developmental</td>
</tr>
<tr>
<td>Mobility</td>
</tr>
<tr>
<td>Psychiatric</td>
</tr>
<tr>
<td>Sensory</td>
</tr>
<tr>
<td>Speech</td>
</tr>
<tr>
<td>Learning</td>
</tr>
</tbody>
</table>
therefore on their ability to access health care.

Health information directed at educating women about menopause and other midlife health issues (e.g., breast cancer, osteoporosis, cardiovascular disease) rarely addresses the particular needs of women with disabilities. Speculations about why this information gap exists include the larger tendency in the literature to desexualize women with disabilities and hence to ignore their specific needs around reproductive health and sexuality. Women with disabilities are often reduced to their disability by health practitioners, which may mean that information about their other health issues is overlooked. Finally, it may also be that the difficulty of isolating the impact of a particular disability on health from the impact of midlife changes acts as a deterrent to this kind of exploration.

In Canada, national surveys have shown a link between gender and disability, with higher percentages of women reporting long-term activity limitations (Statistics Canada, 1994-95 & 1996-97). Women are also found to live longer and therefore are more likely to experience chronic conditions (Statistics Canada, 1996-97). Although the likelihood of having a disability increases with age, some women have disabilities which appear prior to midlife or at birth. Across these groups, women with disabilities are living longer and often remain active and involved in their communities throughout midlife (Welner, 1997). From this we can say that a growing group of women approaching menopause are women with disabilities, which underscores the need for a deeper understanding of these women’s experiences and health care needs.

**B. Introduction to the Study**

This project was initiated by the Pacific DisAbled Women’s Network in recognition of the dearth of information available on the midlife needs of women with disabilities. The idea for the project was formed in discussions about the specific lack of information about midlife changes for women with developmental disabilities. From these discussions a larger study involving women with a range of disabilities was conceived. Using DAWN’s guiding research principles, which foster research by and for women with disabilities, a collaborative partnership with the British Columbia Centre of Excellence for Women’s Health was formed. This collaboration resulted in a research process that was led by women with disabilities and centred on the experiences and voices of women with disabilities.
Examples of the Types of Disabilities Women Reported

<table>
<thead>
<tr>
<th>Category</th>
<th>Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hidden</td>
<td>Asthma, fibromyalgia, chronic fatigue syndrome, diabetes</td>
</tr>
<tr>
<td>Developmental</td>
<td>Down’s syndrome, brain injury</td>
</tr>
<tr>
<td>Mobility</td>
<td>Multiple sclerosis, osteo-arthritis, rheumatoid arthritis, polio</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>Schizophrenia, depression, anxiety</td>
</tr>
<tr>
<td>Sensory</td>
<td>Hearing impairments, blindness</td>
</tr>
</tbody>
</table>

were comprised of greater percentages of persons with hidden disabilities (12/23 and 3/6 respectively). Persons with psychiatric disabilities were spread out between the 35-45 and 46-55 age groups. Persons with sensory disabilities were spread across all ages. The one individual who identified speech as a disability was 59.

C. Research Tool Design

Designing an appropriate tool to investigate the concerns of women at midlife with disabilities was a particular challenge. The tool had to be responsive to the distinct needs of each research participant, while at the same time meet research requirements and the desire to get at the complexities of women’s experiences. A survey tool had to be accessible to women who might not be able to write their own responses or who required the use of plain language to understand the questions. It was recognized that although multiple tools and formats might address women’s specific needs, in the end it would be too methodologically complex to compare the resulting data, especially with the participation of a relatively small number of women.

In the end, the researchers developed a tool that combined interview and survey methods. The result was that each woman was interviewed using an established set of survey questions with a pre-set range of responses. However, during each interview, time was built in for women to respond to some open-ended questions which assessed their perspectives on the relationships between midlife, menopause and their disability. Further, women were encouraged to discuss their perceptions of how well they were coping with the challenges of midlife.

In order to respect each woman’s
needs, a flexible interview process was implemented. For example, women who tire easily were given the option of completing the interview over two sessions.11

D. Participant Recruitment

Thirty-nine interviews were conducted with women with disabilities using the survey questionnaire. Interviews were conducted over the phone and followed an interview protocol.12 Interviews lasted between 45 minutes and one-and-one-half hours and were audio-taped. In addition, 12 interviews with women with developmental disabilities were conducted. These interviews were conducted face to face in the presence of the woman’s caregiver. On the recommendation of an advisory committee member representing this group of women, a decision was made not to audio-tape these interviews. This decision was made based on concerns that women would not be able to fully appreciate the implications of audio-taping and to ensure that women felt as comfortable as possible during the interview.

Attempts were made to solicit the participation of women from across British Columbia. The researchers used DAWN’s extensive contact network to invite women to participate in the research. This included contacting both member and non-member organizations that serve women with disabilities and distributing flyers to advertise the research project. Ads were also placed in local papers describing the research and inviting women’s participation. Participants were taken into the study on a first-come, first-served basis. However, additional efforts were made to solicit the participation of women with developmental disabilities and plans were made for these interviews to be conducted with the assistance of a woman on the advisory committee with a developmental disability.

Specific challenges pertaining to the interviews with women with developmental disabilities arose. In the design of the research much discussion was carried out about how best to respect the specific needs of this group of women without re-enacting the paternalistic relationships to which these women are often subject. The research team members therefore decided that they wanted to hear directly from women with developmental disabilities with minimal mediation from their caregivers. It was felt that because women with developmental disabilities are often in dependent relationships where there is an inherent power imbalance, allowing them the space to discuss their needs and concerns was especially critical.

In reality, partly because of these very conditions, it proved very
difficult to obtain the information from this group of women in a way that would allow for systematic analysis of the data. In light of this, the advisory committee decided that the data was not of a high enough quality to analyze. Subsequently, a decision was made to omit these interviews from the data analysis.

Twenty-three per cent of the participants came from Vancouver and the Lower Mainland and 77% lived in other parts of BC. All of the 12 interviews with women with developmental disabilities were conducted in Vancouver and the Lower Mainland.

Traditional research on midlife and menopause has focused on women between the ages of 40-65. For a number of reasons it was felt that this age catchment would be inadequate for this particular study. Specifically, it is known that women with developmental disabilities (particularly those with Down’s Syndrome) reach menopause at earlier ages (Strong, 1997). Further, the researchers speculated that women with disabilities (especially those that diminish life expectancy) might define the midlife period differently. For this reason participants between the ages of 35-65 were solicited.

The age spread in this study is as follows:

<table>
<thead>
<tr>
<th>Age</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-45</td>
<td>9</td>
</tr>
<tr>
<td>46-55</td>
<td>23</td>
</tr>
<tr>
<td>55-65</td>
<td>7</td>
</tr>
</tbody>
</table>

In this study, all of the women were considered to be in the midlife period on the basis of their age though women were also categorized according to their stages of menopause. So, for example, women were described as premenopausal if they reported no signs of menopause (6 women in our study), as perimenopausal if they had some of the signs of menopause but were still menstruating or had stopped menstruating for less than one year (16 women in our study) and as postmenopausal if their period had stopped for one year or more (17 women in our study). The disabilities that women had were relatively evenly spread across the pre-, peri- and postmenopausal groups.

E. Analysis and Coding

Once the interviews were completed, a data analysis tool was developed in order to code women’s responses. This tool allowed for cross tabulations to be made between a number of different variables, including age, disability and menopausal category. The tool was meant to uncover links and relationships, such as whether women with particular types of disabilities were more informed about
menopause and whether type of disability was related to particular information and education needs with respect to menopause. A more detailed description of these cross-tabulations and their rationale appears in the Research Findings section (section IV) of this report. Each interview was coded according to the data analysis tool and each interview was also looked at as a whole piece to ensure that women’s responses were understood within the particular context of their lives and circumstances. Finally, in the discussion of the results, women’s responses are further contextualized within the existing literature on women with disabilities and midlife.

F. Reporting of Data

Although every attempt was made at consistency throughout the interview process, not all questions in the interview guide were answered by every woman. As such, when the results are recorded in the section below we have chosen to report a number out of the total number of respondents instead of percentages.
Research Findings

A. Going Through the Change: Midlife, Menopause and Disabilities

During the interviews, women were asked a series of questions about changes that they had experienced in the past few years that might be attributed to menopause, their disabilities or midlife in general. Like women in the non-disabled population, the women in this study reported a wide range of social, economic, mental, emotional and physical changes in their lives between the ages of 35 and 65. What was most pronounced, however, was that women in this study could not easily attribute the changes they were experiencing to their disability, to the process of menopause or to other midlife changes. This finding reflects the complexity of the relationship between disability, midlife and menopause and underscores how little is known about their inter-relationship.

1. Social and economic changes

Rita\textsuperscript{15} is a 57-year-old woman who was formally diagnosed with chronic fatigue syndrome three years ago, although she indicated that she had suffered symptoms for the past 10 years. In our discussion, Rita emphasized how difficult it was to maintain a good standard of living because of the ways in which her disability restricted her ability to work. Rita spoke about how her loss of income combined with her ill health had affected her ability to maintain social contacts and an active lifestyle. Although Rita felt that she was coping much better since her diagnosis she still suffered from depression from time to time. Rita described herself as having “sailed through menopause” in part because her life circumstances and her disability had been so difficult in comparison.

Like Rita, other women spoke about fluctuations in their income that were often brought about by either a worsening of their disability (forcing them to reduce or quit their work) or a change in marital status. Women also reported deaths of loved ones, changes in their relationship to their families, and changes which involved moves to new cities. The greatest number of women reported changes in the areas of their personal life, social life, and physical activities. Interestingly, some women also iden-
tified positive changes in their personal and social lives. This is consistent with literature that shows that some women experience a positive period of self-discovery during midlife when the demands of child rearing are often reduced. Similarly to Rita, some women who had had significant life changes during this period reported that these were more challenging than their experiences of menopause.

2. Mental and emotional changes

Jayna is a 51-year-old woman who has diabetes, asthma and several types of allergies. Six years ago Jayna relocated from a large urban centre to a rural area in order to care for her young niece after her brother’s wife died. Prior to this move, Jayna had a high paying career and an active social life. During the interview she spoke about how difficult this life transition had been for her, in part because it coincided with the onset of menopause. She compared her loss of income and the prestige associated with her job in the paid workforce with the unpaid, under-acknowledged work of mothering. Jayna had found it extremely difficult to integrate into her brother’s community and to find paid work; over the past six years she had struggled with depression and suicidal thoughts.

Most women in our study reported increased worry and stress in their lives along with changes in mood and memory. However, a small percentage also reported positive changes in their mood and even more women reported positive changes in their outlook on life. With respect to the latter finding, women described themselves as more accepting of their disabilities and their lifestyles as they aged.

Women generally attributed mental and emotional changes to life events and/or specifically to their disability or illness. For others, like Jayna, this distinction was less clear. Jayna indicated that she did not know whether to attribute her changes in mood to her diabetes, to menopause or to the changes in her lifestyle. A few women felt that their mental and emotional changes were clearly related to menopause, particularly those related to memory, concentration and mood swings.

3. Physical changes

Brenda is a 45-year-old woman who was born with spina bifida. Brenda indicated that her physical health has deteriorated rapidly in the last number of years. Brenda described how she lived with chronic pain in her joints and muscles and how this, combined with the physical changes associated with the onset of menopause, made it impossible for her to work or maintain the social and
recreational activities she had loved in her late 30s.

Women reported a great number of changes related to their health in general. Some of these changes were linked directly to women’s experiences of menopause, for example, hot flashes, night sweats, vaginal and breast changes. In a few instances, women reported night sweats or hot flashes that were related to medications they were taking for their disability or illness. Other changes such as muscle, joint and bone pain were more likely to be attributed to the progression of a woman’s disability or illness.

Changes in energy level were commonly reported, with many women describing several changes over the midlife period. Most of these changes involved a decrease in energy, with only two women reporting increased energy in the midlife period. Again most women attributed these changes to their disabilities (23) or to other midlife events (17). Some women, like Catherine, who has arthritis, did not know whether to attribute changes to their disability or to menopause. Changes in sleep patterns were also common, with 35 women reporting changes both negative (29) and positive (6). Again, most women attributed these changes to their disabilities.

Finally, women reported changes in their appearance, for example, weight, skin and hair changes. Changes in weight were most often attributed to decreased exercise because of physical restrictions resulting from a woman’s disability. Skin and hair changes were more often associated with the general aging process.

4. Sexual intimacy

Monique is a 52-year-old woman who was diagnosed with schizophrenia in her early 30s. In the last five years she has also struggled with rheumatoid arthritis. Monique spoke about how her psychiatric disability had made it difficult to maintain an intimate relationship with her husband, who left her several years ago while she was going through menopause and after she had experienced repeated hospitalizations.

Women were more hesitant to discuss changes in their sexual lives and some women chose not to answer the questions on this topic. A number of women (13) reported physical changes (e.g., increased vaginal dryness) that affected their enjoyment of sex and 16 women reported a decreased interest in sex. Underlying many of the stories that women did relate was a sadness about the loss of sexual experiences or changes in their sexual experiences due to their disabilities/illnesses. Women’s
struggles to attain or maintain sexual intimacy may be seen to reflect society’s desexualization of women with disabilities and older women in general. That is, women’s experiences reflected not only the physical limitations they might experience because of their disability but the difficulty of finding caring and committed partners.

The complex interconnections between midlife, menopause and the natural course of any particular disability made it difficult for women to attribute the physical, social and emotional changes in their lives to a specific cause. For example, when asked about how midlife changes had affected her disability, Karen, who has multiple sclerosis said:

“…not sure, don’t know whether the two are combined…like I don’t know whether my weakness and lack of energy and this kind of thing, I don’t know whether this had to do with my change of life or whether it’s just with my disabilities.”

Valerie, like Karen, had similar difficulties in making this distinction:

“I have noticed that it’s very difficult for me to sort out what might be something perimenopausal and might be something around my illness. I mean the whole issue of fatigue…is that my RA [rheumatoid arthritis] or is that the perimenopause, or is that the two of them working together?”

Finally, Jessica, who has a spinal cord injury, put it this way:

“…how would I know what it is like without it [disability]? …it is a very tough time for me right now…but I couldn’t pinpoint to say well that’s menopause or that’s my disability, it’s probably both, but probably just life in general too…all three of them I suppose.”

The ability of women to relate their changes to menopause seemed to depend a great deal on the temporal relationship between when they got their disabilities and when they started through the process of menopause. Women who developed their disabilities at the same time as going through menopause were least able to distinguish whether their emotional and physical changes were resulting from their disabilities or from menopause. Women who had lived with their disabilities since birth or over a long period of time seemed to be able to more clearly attribute changes they were experiencing to different processes.

5. The effects of midlife changes on a woman’s disability(ies)

Despite this confusion, a number of women made comments about the effects of midlife changes on their disabilities. In this regard, for some
women, like Bernadette, there was a clear link between the progression of her disease (osteo-arthritis) and aging. Judith indicated that her multiple sclerosis symptoms were worse during her menstruation. She wondered whether and in what ways her midlife changes would be affected by her MS. Bridget spoke about how her struggle with depression got worse during menopause and how she had stabilized since going through the change. Debra, who had a number of hidden disabilities (fibromyalgia, chronic fatigue) said, “My pain levels are worse for the 10-day part of my cycle. I think that has changed a great deal over the last year (since entering perimenopause).” Katirina, a woman with a visual impairment, said, “Hard to say unless you could go through life twice…but I would certainly say that the process of aging exacerbates the disability.”

Other women, like Jane, indicated that midlife changes (in her case the responsibility for aging parents) had made it more difficult to cope with her chronic fatigue. This was true for a number of other women who had faced stressful life changes during the midlife period.

Not all women described their midlife changes as having a negative impact on their disability. Frances, who had osteo-arthritis and fibromyalgia, spoke about an increased awareness of the spiritual aspect of life, “Disability and poverty can have an imaginative aspect to it…and we supplement our experiences with resources from books or wherever, you find your fantasy life is enriched…”

6. The effects of a woman’s disability(ies) on midlife changes

On the other hand, women also spoke about how their disability made it harder to cope with midlife changes. Some women felt that their disabilities limited their ability to enjoy the freedom and excitement that some women experience after midlife changes. Others, like Brenda, felt that their disabilities accelerated the aging process. Brenda, who has spina bifida, describes this feeling:

“…I feel generally that I am aging faster than my peer group…I’ve always felt that my life span has been compressed…most of the markers in your life – marriage, children, career – all of those things have been compressed into a much shorter time frame. I often feel that now at 45…I probably have the body and the musculoskeletal workings of someone closer to 60.”

Further, Brenda gave this illustration of how her disability affected her midlife changes:

“I think it makes some of the symptoms [of menopause] seem scarier…and worse than what I understand the
average population experiences. I guess when I have some symptoms… I have… a scarier reaction to them than I should have because I think maybe they’re signalling something else.”

Overall these results can be taken to illustrate the interactions between midlife, menopause and disability. Women’s confusion about what to attribute certain changes in their lives to shows further how little is known with respect to the interaction between midlife events, menopause and disability. It also illustrates the need to better understand the specific interactions between particular disabilities and the processes of menopause.

**B. Midlife Health**

With respect to describing their overall health, many women actually separated the ongoing physical progression of their disabilities from their health in general – feeling that while their disability was getting worse, their overall health was improving. This suggests that the way women were conceptualizing health did not necessarily include physical health. For example, some women indicated that their overall health was good because they never got colds or flus, while others said that their health was good because they had a good outlook on things and were managing well despite their disabilities.

In this section, both women’s perceived midlife health risks and their actual midlife health problems were assessed. First, women were asked to choose from a list of common midlife health risks (bone, heart, breast, nutrition and exercise) to identify areas of concern. Women were then asked to identify health areas where they had personally experienced problems.

1. **Perceived midlife health risks**

Exercise and nutrition emerged as the biggest concerns for women overall. These were followed by concerns about bone health, heart health and breast health. There was a slightly higher level of concern about bone health from women with mobility disabilities. Concerns about heart and breast health appeared to increase with age, while concern about nutrition remained stable across all age groups. The results in this section can be summarized as follows:

<table>
<thead>
<tr>
<th>Health Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone health</td>
<td>29/38</td>
</tr>
<tr>
<td>Heart health</td>
<td>24/38</td>
</tr>
<tr>
<td>Breast health</td>
<td>22/38</td>
</tr>
<tr>
<td>Nutrition</td>
<td>24/30</td>
</tr>
<tr>
<td>Exercise</td>
<td>27/31</td>
</tr>
</tbody>
</table>
Given the high level of concern about exercise, questions were asked regarding the kinds of supports women needed to exercise regularly. There were a wide range of things that women indicated they needed to assist them in exercising. For example, many women indicated that they needed specialized equipment at home, more money and more physical stamina/energy to exercise. A large number of women indicated they would exercise more if they had someone to go with, if the fees for facilities were lower and if they had transportation. Fewer women cited safety, assistance and motivation as things they needed in order to exercise more.

2. Midlife health problems

Most of the midlife health problems that women identified were those that were linked to their disability, especially those related to exercise (35), nutritional habits (21) and bone health (19). Women across every age, disability and menopausal category seemed to identify having the most problems with exercise (more than 80% of women in each age and menopausal category). It is not entirely clear why this is the case, except for the fact that many women indicated that the progression of their disability limited their ability to exercise. For bone, heart, breast and nutrition problems, the results suggest that women have more problems as one moves from the younger to older age categories.

Increasing problems with bones and heart were found as one moves from the mobility, psychiatric, sensory to hidden disability groups (in other words, women with hidden disabilities expressed the most problems with their bones and heart). Breast problems were about the same across the groups with slightly more identified problems in the psychiatric (3/9) and mobility groups (3/10). In the area of nutrition, the largest percentages of women with problems were found in the hidden disability group (12/16) and the mobility disability group (5/10).

Results seem to suggest that women in postmenopause (10/17) have more bone problems than in the no-symptoms (1/6) or perimenopausal group (6/16).

C. Medical Support and Alternative Interventions

Given the number of concerns that women expressed related to their health, questions were asked about the types of medical support and interventions women were currently receiving or had received in the past.

In this study, 32/39 women were taking one or more medications for their disabilities. These medications covered a wide range of drugs such as psychotropic, anti-inflammatory,
anti-spasmodics, anti-hypertensives and painkillers. Women also reported taking dietary supplements, with 26/37 taking vitamins for diet and 18/35 taking supplements like calcium for their bones.

Of the 38 women who answered the question on hormone therapy, 21 were using (or had used) hormone therapy while 17 had not. There appeared to be a slightly higher rate of women in the psychiatric group using hormone therapy and a slightly lower rate of women with mobility disabilities using hormone therapy. Most of the women in this study were not using alternative therapies for menopausal symptoms (32/38) which suggests that these treatments are not widely known or accessible. Those who were using alternative therapies (6/38) were predominantly women with mobility or hidden disabilities.

In order to better understand the use of marijuana for pain or symptom management,16 a number of questions were asked. A small number of women (4/39) in our study indicated that they used marijuana. The women who used marijuana were evenly split between women with mobility and hidden disabilities. The current illegal status of marijuana should give caution to interpreting these numbers since some women may not have felt comfortable disclosing their use.

The women who did use marijuana did so primarily for symptom and pain management. For example, they indicated that marijuana relieved pain, spasms, nausea, and in some cases, women reported that it relieved seizures, hot flashes and aided in breathing.17

The literature suggests that women with disabilities may have difficulty accessing information about menopause from health care practitioners. Further, it is known that most general practitioners do not have information about how particular treatments interact with specific disabilities. In particular, the literature indicates that women with disabilities sometimes have difficulty obtaining certain kinds of health care (e.g., breast and pelvic exams). Accordingly, we asked women to describe their interactions with general practitioners.

Over half of the women in the study (26/39) had spoken with their doctors about midlife changes. Generally, women were satisfied with their communication with their doctors, although several women indicated dissatisfaction and a need for more or better communication.

In our sample, most women did not experience problems with receiving breast exams from doctors (i.e., only one woman reported this difficulty).
More women indicated that they did not do breast self-examinations (10/39) because of their own discomfort.

Although only one woman in our study had been coerced into being sterilized,\(^{18}\) it is now well documented that many women with disabilities, especially those with developmental disabilities, have been subject to forced or coerced sterilizations (Asch & Fine, 1988).

Twelve of thirty-nine women (six women with hidden disabilities, four women with psychiatric disabilities and two women with mobility disabilities) had hysterectomies for reasons associated with their disabilities or other health issues.

### D. Information

#### 1. Perceived knowledge

Part of the purpose of this study was to determine whether or not women themselves felt that they were knowledgeable about midlife changes and to determine in which health areas (bone, heart, breast, exercise and nutrition) they would like more information.

In general, women reported that they were well-informed with respect to midlife changes.

Of the total number of participants (39), 28 felt that they were well-informed about midlife changes, with 11 indicating they felt they were not well-informed. This was also true when women were asked about specific types of treatments. For example, women appeared to be well-informed about the benefits of hormone therapy. By disability, the data is as follows:

<table>
<thead>
<tr>
<th>Knowledge of the Benefits of Hormone Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>7/10 Mobility disabilities</td>
</tr>
<tr>
<td>3/9 Psychiatric disabilities</td>
</tr>
<tr>
<td>2/4 Sensory disabilities</td>
</tr>
<tr>
<td>11/16 Hidden disabilities</td>
</tr>
</tbody>
</table>

A similar pattern was notable across the groups for knowing the risks of hormone therapy.

It is interesting to note that although the women with mobility disabilities were more informed about hormone therapy, they were less likely to be using hormones, while the women with psychiatric disabilities were more likely to be using hormones but reported that they wanted more information about them. It may be that women with mobility disabilities are more health-conscious than other groups by necessity and therefore request this kind of information from their doctors, while the contacts that women with psychiatric disabilities have with health professionals may not regularly include information about hormone therapy.
As one would expect, age and menopausal stage seemed to predict how well women were informed. The older the age of the participant, the more likely she was to feel that she was well-informed about midlife changes.

There was a slight increase through the stages of menopause in the percentage of women who felt that they were well-informed:

<table>
<thead>
<tr>
<th>Stages of Menopause</th>
<th>Well - informed</th>
</tr>
</thead>
<tbody>
<tr>
<td>No symptoms</td>
<td>4/6</td>
</tr>
<tr>
<td>Perimenopausal</td>
<td>11/16</td>
</tr>
<tr>
<td>Postmenopausal</td>
<td>13/17</td>
</tr>
</tbody>
</table>

When looking at the participants’ responses according to their disability, women with psychiatric disabilities described themselves as the least informed (5/9). This might suggest that materials designed for this particular group are necessary.

2. Information needs

On the surface there appear to be some contradictions in the ways in which women answered questions related to their knowledge vs. their needs for information. For example, although women reported themselves to be well-informed about midlife changes and treatments for menopause, they also indicated that they wanted more information, through not necessarily on the specific topics mentioned. When women were asked if they wanted more information specifically on bone, heart, breast and nutritional health, more than half of the women who answered each of these questions indicated that they did not want more information. What this suggests is that women have information needs beyond those related to general knowledge about menopause.

A good example of this is in the area of hormone therapy where women indicated they were well-informed but wanted more information about how hormone therapy interacts with specific disabilities. Generally, it was true that women wanted more specialized and specific forms of information relating to their particular disabilities and the process of menopause. As well, many women expressed an interest in learning more about alternative therapies.

In addition to needs for specific kinds of information, women also wanted concrete things to help them cope. Approximately half of all the women wanted someone they could share their concerns and needs with on a more regular basis. Women with psychiatric disabilities especially wanted help with personal care (3/9), while women with hidden disabilities wanted help with homemaking (8/16) because many of them had illnesses with symptoms of fatigue.
Discussion

“I missed my loss of activities with my arthritis much more than I missed my ovaries . . . and I have gone through the physical changes that happen . . . when your hormones all change . . . your hair changes, dryness of skin . . . I’ve had all those changes . . . I can live with those losses; they are minor compared to the losses that I’ve had with the arthritis.”

Gwen’s words echo the feelings expressed by many women in this study. Most women had had very difficult lives, marked by significant events during the midlife period. Additionally, many women spoke about their struggles with their disabilities. These two themes were often linked, that is, many women had gone through huge transitions in their personal and social relationships during their midlife years due to the progression of their disabilities. For other women, disabilities began either during or around the time of menopause or after a significant experience during midlife. In this respect, women’s experiences of midlife changes and of their disabilities often took precedence over their experiences of menopause.

Women spoke especially about the financial and social barriers they experienced as a result of disability. Women described themselves as struggling to make ends meet after partners left them and about how difficult it was to survive on disability pensions. In particular, women noted that financial restrictions meant that they could not avail themselves of proper nutrition, vitamins, exercise equipment and alternative therapies that might have eased the symptoms they experienced as a result of menopausal changes.

Social isolation and the loss of intimate relationships was another strong theme throughout the interviews. Women repeatedly indicated that they needed more social support, including caring partners and groups where they could connect with other women experiencing similar difficulties.

The physical difficulties women experienced as a result of their disabilities could often not be separated or distinguished from the physical changes...
they experienced during menopause. This reflects the lack of information that is currently available about the specific interactions between particular disabilities and menopause, including information about the interactions of medications. Women were clearly not getting this kind of information from medical practitioners, from the popular media, or from specialized women’s health information packages on menopause and midlife changes. Lisa, who has a spinal cord injury, indicated, “There should be a lot more support for the disabled…there’s just not enough support out there at all, I don’t think, even on the internet…it’s really hard to come across anything…what there is, is so shallow.”

Clearly, in order to provide women and health care practitioners with this information, more research is needed which investigates the physical and emotional challenges women with disabilities experience at midlife. Specific attention should be paid to distinctions between different types of disability (i.e., physical, psychiatric and mental) and age of disability onset. Health care practitioner education on the challenges faced by women with disabilities entering menopause is particularly critical so that women are receiving the best care possible and are able to make informed health care decisions.

Although we support developments in the field of women’s health that positively re-frame women’s experiences of menopause, empowerment approaches will only be useful to women with disabilities if they acknowledge the very real struggles these women face. Materials must address not only the physical limitations women with disabilities experience but also the social conditions (e.g., poverty, violence and discrimination) which limit their choices.

Our study highlights the methodological challenges associated with defining disability and in accessing the experiences of women with developmental disabilities. In the former case, it is important that future research address questions related to defining disability in order to ensure a more comprehensive and accurate understanding of a range of disabilities and women’s experiences of them. In the latter case, researchers must include women with developmental disabilities in their work in ways that would allow them maximum autonomy in the research interview process while maintaining a research design that is methodologically sound. Studies designed specifically around this population of women are necessary, especially those which engage the skills and knowledge of women with developmental disabilities themselves.
Recommendations

A. Further Research

It is clear that a wide range of further research is needed to better understand the relationships between midlife, menopause and disability. In order to accomplish this kind of research in ways that take into account the complexities of these relationships as well as the lived experiences of women with disabilities, further methodological and research design development is also needed. We recommend the following:

- The development of methodologies and research designs that take into account the complex political and definitional problems associated with disability that we have outlined in this report.

- The development of methodologies and research designs that actively involve women with disabilities in the development and carrying out of the research.

- The development of methodologies and research designs that can effectively access the experiences of women with developmental disabilities at midlife.

- Research which systematically looks at the inter-relationships between midlife, disability and menopause. This research should simultaneously examine the biological, physiological and social aspects of midlife and disability.

- Research that gathers accounts from women with disabilities about their experiences in midlife.

- Research that will provide disability-specific information about menopause and the treatments (both medical and alternative) for menopausal symptoms.

B. Education Materials

In order to address the gaps in the knowledge that health care professionals currently have with respect to women with disabilities, midlife and menopause, we make the following recommendations about education:
That health care professionals be educated according to the findings of emerging research about the inter-relationships between midlife, menopause and disabilities.

Materials should be developed that take into account the particular experiences of women with disabilities, especially materials which acknowledge systemic barriers faced by this group of women. These materials should then be used to educate health care professionals.

That health care professionals receive education which outlines medical information about the impact of menopause on particular disabilities, including information about the interactions of medications.

That health care professionals be made aware of alternative treatments for menopausal symptoms.

C. Information

Women in our study expressed the need for more information that specifically addresses issues related to disability and menopause. We recommend that the following information be developed for women:

Materials on menopause and midlife that take into account the particular experiences of women with disabilities, especially materials which acknowledge systemic barriers faced by this group of women.

Materials that provide specific medical information about the impact of menopause on particular disabilities, including information about the interactions of medications.

Materials on alternative treatments for menopausal symptoms.
Appendix 1: Questionnaire/Interview Guide
A. DEMOGRAPHICS (General Information)

A.1. What city or town do you live in?

A.2. How old are you?
☐ 35 - 45  ☐ 46 - 55  ☐ 56 - 65  ☐ Over 65

B. DISABILITIES

B.1. Do you have any of the following disabilities? Please check ALL that apply to you.
☐ Mobility/Walking
☐ Visual
☐ Hearing
☐ Psychiatric (Mental health: severe depression or anxiety or others)
☐ Learning
☐ Developmental (Labelled mentally disabled or mentally handicapped)
☐ Hidden (For example: severe diabetes, allergies, heart problems or others)
☐ HIV/AIDS
☐ Other (Please list) __________________________________________________________

B.2.a What is your disability? ____________________________________________________

B.2.b. How long have you had a disability? ☐ ☐ Years

Check here if you are not sure how long you have had a disability: ☐
B.3. Do you take medication that was given to you by your doctor related to any of the above problems that you may have?

☐ Yes  ☐ No  ☐ Not sure

B.4. If YES, what medications do you take?

________________________________________________________________________________

B.5. Do you use any of the following aids on a regular basis? Please check all that apply to you.

☐ Wheelchair or scooter

☐ Crutches, cane or walker

☐ White cane or assistive animal

☐ Hearing aid

☐ Urinary catheter

☐ Stoma

☐ Feeding tube

☐ Respirator

☐ Other (Please specify) __________________________________________________________________

B.6. Do you use any of the following on a regular basis?

☐ Plain language  ☐ Sign language  ☐ Braille  ☐ None of these

Additional comments on this question:

_________________________________________________________________________________________
C. MIDLIFE CHANGES

C.1. Do you feel that you are well informed about midlife changes in general?
☐ Yes ☐ No ☐ Not sure

C.2. Do you feel that you would like more information about midlife changes?
☐ Yes ☐ No ☐ Not sure

C.3. Personal Changes
Have any of the changes listed below occurred in your life?
Please check all that apply to you and give a brief explanation for each change that you check.

☐ Income

☐ Paid work

☐ Unpaid work

☐ Place of residence

☐ Friendships

☐ Intimate relationship

☐ Relationships with family members

☐ Death of a loved one

☐ Pets

☐ Activities

☐ Other changes you have noticed

Additional comments on this question:
C.4. Mental or Emotional Changes
Since you have entered midlife changes, have you noticed any changes that have occurred in the following?
Please check all that apply to you and explain the change

☐ Memory ☐ Better  ☐ Worse  ☐ Same
☐ Concentration ☐ Better  ☐ Worse  ☐ Same
☐ Getting angry ☐ More  ☐ Less  ☐ Same
☐ Stress level ☐ Up  ☐ Down  ☐ Same
☐ Mood ☐ Better  ☐ Worse  ☐ Same
☐ Outlook on life ☐ Better  ☐ Worse  ☐ Same
☐ Worry ☐ More  ☐ Less  ☐ Same
☐ Interest in things I used to do ☐ More ☐ Less  ☐ Same

☐ Other changes

Additional comments on this question:

__________________________________________________________________________________________

__________________________________________________________________________________________

THE CHALLENGES OF CHANGE: THE MIDLIFE HEALTH NEEDS OF WOMEN WITH DISABILITIES 37
C.5. Physical Changes
Since you have entered midlife changes, have you noticed any major changes that have occurred in the following? Please check all that apply to you, and explain the change.

### C.5.1 Changes in General Health and Well Being

<table>
<thead>
<tr>
<th>Health in general</th>
<th>Better</th>
<th>Worse</th>
<th>Same</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision</td>
<td>Better</td>
<td>Worse</td>
<td>Same</td>
</tr>
<tr>
<td>Urine control</td>
<td>Better</td>
<td>Worse</td>
<td>Same</td>
</tr>
<tr>
<td>Hot flashes</td>
<td>More</td>
<td>Less</td>
<td>Same</td>
</tr>
<tr>
<td>Night sweats</td>
<td>More</td>
<td>Less</td>
<td>Same</td>
</tr>
<tr>
<td>Headaches</td>
<td>More</td>
<td>Less</td>
<td>Same</td>
</tr>
<tr>
<td>Pain in joints or bones</td>
<td>More</td>
<td>Less</td>
<td>Same</td>
</tr>
<tr>
<td>Pain in muscles</td>
<td>More</td>
<td>Less</td>
<td>Same</td>
</tr>
</tbody>
</table>

☐ Other changes you have noticed

Additional comments on this question:

---

### C.5.2 Changes in Energy Level

<table>
<thead>
<tr>
<th>Energy Level</th>
<th>More</th>
<th>Less</th>
<th>Same</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep</td>
<td>More</td>
<td>Less</td>
<td>Same</td>
</tr>
</tbody>
</table>

☐ Other changes you have noticed
C.5.3 Changes in Appearance

- Weight  ○ Up  ○ Down  ○ Same
- Height  ○ Up  ○ Down  ○ Same
- Skin
- Hair
- Other changes you have noticed

C.5.4 Changes in Menstrual Period

- Length of your menstrual period  ○ Longer  ○ Shorter  ○ Same
- Amount of flow in your menstrual period  ○ More  ○ Less  ○ Same
- Missed periods (How often?)
- Periods have stopped (How long ago?)
- Other changes you have noticed

C.5.5 Sexual Changes

- Comfort during sex  ○ More  ○ Less  ○ Same
- Interest in sex  ○ More  ○ Less  ○ Same
- Vaginal changes  ○ Wetter  ○ Dryer  ○ Same
- Other changes to your body that you have noticed
C.5.6. Changes in Breast

☐ Tenderness  ○ More  ○ Less  ○ Same

☐ Lumps  ○ More  ○ Fewer  ○ Same

☐ Other changes that you have noticed

Additional comments on any part of Question 5:

C.6. Approaches to Midlife Changes

C.6.1. Have you talked to your doctor about any of the midlife changes you have experienced?

☐ Yes  ☐ No  ☐ Tried to

C.6.2. If YES, were you satisfied with the information that was given to you?

☐ Yes  ☐ No  ☐ Not sure

C.6.3. Has your doctor prescribed hormones for menopause symptoms?

☐ Yes  ☐ No  ☐ Not sure

C.6.4. If YES, how do you feel about your decision to take hormone replacement therapy?

C.6.5. Do you know about the benefits of hormone therapy?

☐ Yes  ☐ No  ☐ Not sure

C.6.6. Do you know about the risks of hormone therapy?

☐ Yes  ☐ No  ☐ Not sure

C.6.7. Do you feel that you need more information about hormone therapy?

☐ Yes  ☐ No  ☐ Not sure
C.6.8. Do you take alternative therapy, such as herbs, for menopause symptoms?

☐ Yes  ☐ No  ☐ Not sure

C.6.9. If YES, how do you feel about your decision to take alternative therapy for menopause symptoms?

C.6.10. Do you feel that you need more information about alternative therapy for menopause symptoms?

☐ Yes  ☐ No  ☐ Not sure

Additional comments on any part of Question 6:
D. STERILIZATION/HYSTERECTOMY

D.1. Has your uterus been surgically removed?  □ Yes  □ No  □ Not sure

D.2. If YES, how old were you?  □□□□ Years old

Check here if you are not sure how old you were: □

D.3. Were you forced to have your uterus removed?  □ Yes  □ No  □ Not sure

D.4. Have your ovaries been surgically removed?  □ Yes  □ No  □ Not sure

D.5. If YES, how old were you?  □□□□ Years old

Check here if you are not sure how old you were: □

D.6. Were you forced to have your ovaries removed?  □ Yes  □ No  □ Not sure

D.7. If you have had your uterus and/or ovaries removed, do you feel that you were informed well enough about the operation and the results?

□ Yes  □ No  □ Not sure

D.8. How do you feel about what happened?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Additional comments on any of the questions in Section D:

__________________________________________________________________________

__________________________________________________________________________
E. MIDLIFE HEALTH RISKS

E.1 Bone Health

E.1.1. How concerned are you about your bone health related to your midlife changes?
☐ A lot  ☐ Some  ☐ A little  ☐ Not at all

E.1.2. Are you having any problems with your bones that you believe are related to midlife changes?
☐ Yes  ☐ No  ☐ Not sure

E.1.3. Are you taking medication or dietary supplements for bone health?
☐ Yes  ☐ No

E.1.4. Has anyone in your family had problems with osteoporosis or other bone problems after midlife? E.g. mother, father, sister, brother, etc.
☐ Yes  ☐ No  ☐ Not sure

E.1.5. If YES, please list who: __________________________________________________________
  __________________________________________________________

E.1.6. Do you feel that you need more information about bone health?
☐ Yes  ☐ No  ☐ Not sure

Additional comments on this question:
__________________________________________
__________________________________________
__________________________________________
E.2 Heart Health

E.2.1. How concerned are you about your heart health after your midlife changes?

☐ A lot  ☐ Some  ☐ A little  ☐ Not at all

E.2.2. Are you having any problems with your heart that you believe are related to your midlife changes?

☐ Yes  ☐ No  ☐ Not sure

E.2.3. Have you started taking any medications or dietary supplements for your heart health since your midlife changes began?

☐ Yes  ☐ No

E.2.4. Has anyone in your family had heart problems? E.g. mother, father, sister, brother, etc.

☐ Yes  ☐ No  ☐ Not sure

E.2.5. If YES, please list who:

________________________________________________________________________

________________________________________________________________________

E.2.6. Do you feel that you need more information about heart health?

☐ Yes  ☐ No  ☐ Not sure

Additional comments on this question:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
E.3 Breast Health

E.3.1. How concerned are you about your breast health related to your midlife changes?

☐ A lot    ☐ Some    ☐ A little    ☐ Not at all

E.3.2. Have you had any breast problems since your midlife changes began?

☐ Yes    ☐ No    ☐ Not sure

E.3.3. If YES, please explain:  

E.3.4. Have you had any problems getting the following examinations?  
Please check all that apply to you and give a brief explanation.

☐ Breast examination from your doctor

☐ Breast screening or diagnostic mammogram

E.3.5. Do you have problems doing self-examinations of your breasts? If yes, please explain.

☐ Yes    ☐ No

E.3.6. Have you ever had breast cancer? ☐ Yes    ☐ No

E.3.7. If YES, in what year were you diagnosed?  

☐ 19

Check here if you are not sure what year it was.

E.3.8. Has anyone in your family been diagnosed with breast cancer? E.g. mother, father, sister, brother, etc.

☐ Yes    ☐ No    ☐ Not sure

E.3.9. If YES, please list who:  

E.3.10. Do you feel that you need more information about breast health?

☐ Yes    ☐ No    ☐ Not sure

Additional comments on this question: 
E.4. Food

E.4.1. Have you changed the kind of foods or drinks that you eat or do not eat because of midlife changes?

☐ Yes  ☐ No

E.4.2. If YES, please explain: __________________________________________________________

________________________________________________________________________________

E.4.3. Does your disability limit foods that are necessary for midlife health?

☐ Yes  ☐ No  ☐ Not sure

E.4.4. If YES, please briefly describe your diet: _________________________________________

________________________________________________________________________________

E.4.5 Do you take vitamins to supplement your diet?

☐ Yes  ☐ No  ☐ Sometimes

E.4.6. If you do NOT take vitamins, why not?

☐ Too expensive

☐ Too much bother

☐ I do not think I need them

☐ Other (Please explain) _____________________________________________________________

E.4.7 Do you take calcium to supplement your diet?

☐ Yes  ☐ No  ☐ Sometimes

E.4.8 If you do NOT take calcium, why not?

☐ Too expensive

☐ Too much bother

☐ I do not think I need them

☐ Other (Please explain) _____________________________________________________________

E.4.9. Do you feel that you need more information about good nutrition?

☐ Yes  ☐ No  ☐ Not sure
F. EXERCISE

F.1. How often did you exercise before your midlife changes started?

☐ More than 3 times a week ☐ 3 times a week ☐ Less than 3 times a week ☐ Never

F.2. How often do you exercise now?

☐ More than 3 times a week ☐ 3 times a week ☐ Less than 3 times a week ☐ Never

F.3. Do you think you should exercise more?

☐ Yes ☐ No ☐ Not sure

F.4. Which of the following exercises does your disability limit you from? Check all that apply.

☐ My disability does not limit me from exercising. ☐ Aerobics

☐ Standing ☐ Weight bearing exercise

☐ Walking ☐ Weight lifting

☐ Running ☐ Other (Please explain)

☐ Swimming

F.5. Which of the following supports do you need in order to exercise or to exercise more often? Check all that apply.

☐ Access to gym and/or swimming pool ☐ Lower fees to use the gym or pool

☐ Transportation ☐ A safe route to the gym or pool

☐ An attendant ☐ A place where I feel safe

☐ Someone to go with ☐ Other (Please explain)

☐ Child care
G. SMOKING

G.1. Do you smoke or use other tobacco products? □ Yes □ No □ Sometimes

G.2. Why do you use tobacco? Check all that apply.

□ Social reasons □ It relieves hot flashes

□ Cultural reasons □ It relieves pain

□ To relax □ It relieves nausea

□ I am addicted to tobacco □ Other (Please explain)

□ It relieves spasms

G.3. Do you use marijuana? □ Yes □ No □ Sometimes

G.4. Why do you use marijuana? Check all that apply.

□ Social reasons □ It relieves hot flashes

□ Cultural reasons □ It relieves pain

□ To relax □ It relieves nausea

□ I am addicted to marijuana □ Other (Please explain)

□ It relieves spasms

Additional comments on Section G:
H. SUMMARY

H.1. Have you experienced changes in your disability that may be related to midlife changes?

☐ Yes  ☐ No  ☐ Not sure

H.2. If YES, how has your disability or disabilities changed?


H.3 Over all, how well do you feel that you cope with your midlife changes?


H.4. In general, how has your disability or disabilities affected your midlife changes, including menopausal changes?


H.7. What do you feel that you need to help you cope with all of these changes? Check all that apply.

☐ More information about midlife changes

☐ More information about menopause

☐ Someone to talk to about my changes and how I feel

☐ More help with my personal care

☐ More help with my home making

☐ To get out with people more often

☐ Other (Please explain)
H.4. Your Comments
Please use this page and the back of the survey pages for any comments you would like to make:
- about your experiences with midlife change and/or menopause,
- about anything important that was not brought up already in this questionnaire/survey guide,
- about any of the questions asked.
Appendix 2

Midlife Needs of Women with Disabilities

Project Information

This is a research project on the midlife needs of women with disabilities. This project is funded by the Health Transition Fund, Health Canada, and is co-sponsored by Pacific DAWN: Pacific DisAbled Women’s Network and the BC Centre of Excellence for Women’s Health.

Midlife change or change of life is usually considered to be menopause. However, there are many changes that happen in midlife:

- we have become older and may need help or may need more help,
- children have grown up and left home,
- parents have become elderly and may need care,
- job situations change, home situations change,
- our bodies and our emotions change as we approach and go through midlife.

All of these changes affect how we feel about ourselves and how we manage to cope with the changes.

In trying to assess the needs of women with disabilities during this time of life you will be asked about all of your midlife changes and how you cope with them. Midlife changes may mean different things to different women. We want to find out if women with disabilities experience midlife changes, including menopause, differently than non-disabled women. We want to know if midlife changes affect your disability and if your disability affects your midlife changes.

If you have any questions or concerns about this project, please contact:

Shirley Masuda, Project Coordinator,
Pacific DAWN: Pacific DisAbled Women’s Network
Tel: (604) 270-1920; Fax: (604) 273-7249 or
BC Centre of Excellence for Women’s Health
Tel: (604) 875-2633; Fax: (604) 875-3716
Midlife Needs of Women with Disabilities

Consent Form

I give my permission to be interviewed for the project entitled: “Midlife Needs of Women with Disabilities.”

I understand that the data collected will be used to examine the midlife experiences of women with disabilities.

I understand that I am agreeing to participate in an in-person or telephone interview for about 1 hour.

I understand that this interview will be recorded on tape only if I allow the interviewer to do so.

I understand that any interview record will be stored safely, and destroyed after the project is completed.

I agree to permit the researchers to publish the results of my interview as long as I cannot be identified.

I understand that the research team guarantees my confidentiality.

I understand that my decision to participate is voluntary and that my consent can be withdrawn by me at any time simply by informing a member of the research team that I revoke this consent. I further understand that I will still receive my honorarium money.

Full name printed: ______________________________________________

Signature: ____________________________________________________

Date: ________________________________________________________
Endnotes

1 Throughout this report we have chosen to use the term “disability” to refer to both disabilities and/or chronic illnesses.

2 A list of these guidelines is found in this report after the table of contents.

3 For example, disabled women have sometimes taken differing positions on new reproductive technologies from non-disabled women, especially those technologies related to genetic screening.

4 There are some notable exceptions to this, for example, work which examines the specific needs of women with developmental disabilities (Schlaier, 1996; Sonpal-Valias, 1998).

5 For example those gathered by Statistics Canada for the 1991 Census.

6 For example, of the 36 women who responded to questions about the length of their disability, the majority of the women in all disability groups had had their disabilities for more than five years (but not since birth). Women with mobility or sensory disabilities were more likely to have had their disabilities since birth (2/10 and 1/4, respectively). Women with hidden disabilities were the most likely participants to have had their disabilities for less than five years.

7 For example, in this study, 11 women reported having only one disability, while 13 reported having two disabilities and seven reported four or more disabilities.

8 In the chart these are presented as secondary disabilities.

9 Sensory included hearing and visual disabilities.

10 Speech is not usually seen as a primary disability, however, there was one woman in our study who identified it this way even though her speech problems stemmed from cerebral palsy.

11 See Appendix 1 for the full interview guide and questions.

12 A copy of the form explaining the project to participants and a copy of the consent form can be found in Appendix 2.
In one locale (Victoria), a news article on the study resulted in an especially enthusiastic response from women.

Some women in our study had had hysterectomies. If a woman had had a complete hysterectomy (i.e., removal of both ovaries and uterus) she was considered post-menopausal. Women who had had partial hysterectomies (i.e., still had one or two of their ovaries) were classified according to their own self-definitions as to whether they had experienced menopause. For example, some women in this group indicated that they were experiencing perimenopausal symptoms.

The names used in this report are pseudonyms and identifying information has been changed to protect anonymity.

Currently, in Canada and in the US, marijuana use has been legislatively approved for use by persons with certain physical conditions. However, in practice, doctors are still reluctant to give their patients prescriptions because the College of Physicians and Surgeons had recommended against such prescription. The highest court in Ontario has given the federal government a deadline (until 2001) to make medicinal marijuana accessible to those in need.

It is interesting to note that when women were asked about tobacco use, 11 of the 17 women who smoked indicated they did so for relief of nausea, spasms and hot flashes.

It is important to note that not all women would necessarily be aware of having been sterilized. This is particularly true of women with developmental disabilities.
Advisory Committee

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DisAbled Women’s Network

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References


"THE CHALLENGES OF CHANGE: THE MIDLIFE HEALTH NEEDS OF WOMEN WITH DISABILITIES" 57


Ce rapport de recherche sur la santé des femmes est offert en français et sous des formes utilisables par les personnes handicapées. Pour plus de détails, veuillez communiquer avec le Centre d’excellence de la C.-B. pour la santé des femmes.