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Her Choice, Her Voice: An Exploration of Women Centred Health Care

By

Barat Jade Wolfe

A Dissertation Submitted to the faculty of Graduate Studies through the Department of Psychology in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy at the University of Windsor

Windsor, Ontario, Canada

2012

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Her Choice, Her Voice: An Exploration of Women Centred Health Care

by

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## **AUTHOR'S DECLARATION OF ORIGINALITY**

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#### ABSTRACT

Patient perspectives are increasingly acknowledged as key indicators of health care quality, and the utilization of health services. Given the recent cutbacks to women's health services and governing organizations in Ontario, women's perspectives are particularly important to help understand the impact of these decisions. The purpose of this study was to determine if and how women centred care was being employed in Ontario women's health centres, and to explore women's experiences with this paradigm of care. Four directors of women's health centres completed an online survey to assess the extent to which Hills and Mullett's (2005) women centred mandate was being employed in Ontario. A content analysis revealed that directors largely believed they employed all of Hills and Mullet's principles. Interviews with seven women were also conducted to elicit narratives of their experiences at women's health centres. Using Interpretive Phenomenological Analysis (IPA) and an intersectional framework, four major themes were found: Women's health centres as an alternative to other care, Experiences at women's health centres, Defining and navigating health services, and Understanding and contributions of "the self." These findings indicated that the women were invested in their health, valued women's health centres, and desired a greater voice in defining their health services. These findings also revealed limitations in our health system. Namely, women's experiences and understandings of the system are different than those of their providers. Implications of these findings are discussed and future directions identified.



iv

### ACKNOWLEDGEMENTS

Over the course of six years, and through the rollercoaster ride that is a doctoral degree, I have been supported by so many exceptional individuals. In terms of my dissertation itself, I have several people to acknowledge. I extend my thanks to Dr. Fuschia Sirois for sticking with me through time and distance; we finally did it! To my committee members Dr. Charlene Senn, Dr. Julie Fraser, and Dr. Debbie Kane, I express my gratitude for your unending support and outstanding feedback; my dissertation is infinitely better for your contributions. To Dr. Marilyn Ford-Gilboe, I thank you for your thoughtful comments and questions at my defense; you have helped me clarify my future research goals. I must also thank Dr. Erik Backlund for his feedback, support, and kick-in-the-ass; you were there when I needed someone most. Lastly, to Colleen Coakley, Bre Lubbers, HoiYan Tang, and Rebecca Wolfe, thank you for your help with transcription and editing my references.

I could not have navigated graduate school without the support of several important others. I am grateful for Dr. Greg Chung-Yan and his willingness to let me hijack his day in order to work through my problems; thank you for your time, support, resources, and wisdom. I must also thank the entire Department for helping me along the way; it was truly a group effort to get me through. In particular, my thanks go to Dr. Charlene Senn, Dr. Dennis Jackson, Dr. Robert Orr, Barb Zakoor, and Penny Linton for your various contributions to my successes. I was also fortunate enough to work with and for many other outstanding individuals over the years. I must express my gratitude to Dr. Nombuso Dlamini, Dr. Jerry Tan, Dr. Sheila Cameron, and Dr. Jim Wallace for the opportunities you gave me, your support, and for making me a better educator and researcher.

Although it would be impossible to thank every single person who stood with me (and behind me) during the last several years, I would be remiss if I did not acknowledge the love and support of my friends and family. To Kathy, JoJo, Melissa, Andrea, Ashley, Terry, Carrie, Simmy, Amy, Erik, and all the other amazing women and men in my life, thank you for your friendship, love, and support; you always had my back. I would not have made it without leaning on you, and hope you know that you can always lean on me. To Tony and the entire Maci family, I give my love and gratitude; you opened your hearts and home to me, and were a pillar of strength during some very tough years. To Wes and Kenton, thank you for making me laugh and for telling me I could do anything. To Bec, it is so hard to express the role you have played in this process; from the time we were little, you have believed in me and fought for me the way no one else ever has (even if that meant standing up to bullies with a She-Ra umbrella). Thank you for supporting me no matter what mistakes I made. To my parents, I simply say thank you for everything; this would have been impossible without your love, time, and support, both emotional and financial. In everything I do, I do it with the hope of making you proud of me. Thank you and I love you.

Lastly, to all the women I surveyed and interviewed, I offer my sincere thanks. The only reason this dissertation exists is because you were willing to open up to me and share your thoughts, hopes, and personal experiences. I only hope I have done your stories justice and that together, we can create the social change that is so clearly needed. Thank you.



## **TABLE OF CONTENTS**

AUTHOR'S DECLARATION OF ORIGINALITY	iii
ABSTRACT	iv
ACKNOWLEDGEMENTS	v
LIST OF TABLES	ix
LIST OF FIGURES	X
LIST OF APPENDICES	xi

## CHAPTER

I. Introduction	1
Women and the Canadian Health Care System	
Contributions of the Women's Health Movement	5
Approaches to Understanding Women's Health	9
Women's Health Needs	
Women Centred Care	17
Conceptual definitions	17
Women's health centres	
Patient centred care	
Family centred care	
Woman centred care: The case of midwifery	
Implications of women centred care	
The need for research	
The Present Study	
Purpose and research questions	
II. Methodology	
Qualitative Methodology	
Feminist Framework	
Intersectionality	
Researcher's Role and Challenges Faced	
Phase One: Profiles of Women's Health Centres	
Participants	
Methods	
Data analysis and considerations	
Phase Two: Women's Stories	45
Participants	45
Methods	46
Data analysis	
Evaluative criteria and ethical considerations	52



III. Results and Discussion: Phase One and Preamble to Phase Two	55
Phase One : Profiles of Women's Health Centres	55
Phase Two : Women's Stories	59
Vignettes	61
Participant 1: Jane	61
Participant 2: Patty	63
Participant 3: Julie	65
Participant 4: Sarah	67
Participant 5: Laura	68
Participant 6: Cheryl	
Participant 7: Helen	
Researcher: Barat	
Interpretive Phenomenological Analysis	75
Summary	
IV. Women's Health Centres as an Alternative to Other Care	
Dissatisfaction and Mistrust	
Perceived weaknesses	
Marginalization	
Lack of services	
Seeking an Alternative: A Meaningful Decision	
Gaining awareness	
The value placed on women's health	
The effort to seek access	
V. Experiences at Women's Health Centres	
Perceptions of Care	
Strengths	
Weaknesses	
Role of Connectivity	
Sense of community	
Role of advocacy	
Need for involvement	
VI. Defining and Navigating Health Services	
Defining Ideal Women's Health Services	
What women's health services should include	
What women's health services should not include	135
Navigating Health Services	138
Withdrawing from care	
Fractured care	144



VII. Understanding and Contributions of "the Self"	
Role of Self-Identity	
Uniting women's experiences	
Differentiating women's experiences	
Other important factors	
VIII. Conclusions	
Chapter III	
Chapter IV	
Chapter V	
Chapter VI	
Chapter VII	
Limitations	
Final Thoughts	
REFERENCES	
APPENDICES	
VITA AUCTORIS	



## LIST OF TABLES

Table 1. Summary of women's health centres	45
--------------------------------------------	----



## LIST OF FIGURES

Figure 1.	Visual rep	presentation of th	he IPA73
0	1		



## LIST OF APPENDICES

APPENDIX A: Recruitment Notice	
APPENDIX B: Women's Health Centres in Ontario	
APPENDIX C: Consent to Participate in Research	
APPENDIX D: Online Survey with Directors of Women's Health Centres	
APPENDIX E: Profile of Women's Health Centre #1	
APPENDIX F: Profile of Women's Health Centre #2	
APPENDIX G: Profile of Women's Health Centre #3	
APPENDIX H: Profile of Women's Health Centre #4	
APPENDIX I: Online Recruitment Notice	
APPENDIX J: Letter of Information and Consent for Participants	
APPENDIX K: Interview Agenda	
APPENDIX L: Transcription Confidentiality Agreement	
APPENDIX M: Participant 1 Analysis Table	
APPENDIX N: Participant 2 Analysis Table	
APPENDIX O: Participant 3 Analysis Table	
APPENDIX P: Participant 4 Analysis Table	
APPENDIX Q: Participant 5 Analysis Table	
APPENDIX R: Participant 6 Analysis Table	
APPENDIX S: Participant 7 Analysis Table	
APPENDIX T: Master Table of Superordinate Categories	



### CHAPTER I

#### Introduction

Increasingly, the fields of health and medicine are acknowledging the importance of exploring patients' perspectives in health-related research. In particular, patients' perceptions of health care are a key indicator of quality (Frojd, Swenne, Rubertsson, Gunningberg, & Wadensten, 2011) and an important factor in determining utilization of health services (Bertakis, Azari, Helms, Callahan, & Robbins, 2000). However, much of the body of literature related to "listening" to patients has been framed from the perspective of face-to-face interactions with providers: that is, listening to patients' stories as a means of informing and humanizing each individual health care encounter (Lees, 2011), rather than invoking change at the hospital (or larger) level (Frojd et al., 2011). Research that has looked at patients' perceptions beyond the patient-provider interaction has been focused almost solely on satisfaction with health services. Unfortunately, satisfaction research can be problematic; satisfaction ratings, which tend to be high, cannot indicate areas of improvement and do not show what matters to patients (Sitzia & Wood, 1997). This approach to seeking patients' perspectives has ultimately ensured that patients have a limited and passive role in influencing health care (Coulter & Fitzpatrick, 2000). Although efforts to incorporate a richer understanding of patient experiences have improved in the last decade, it is clear that more work needs to be done.

The need to include patient voices and experiences as a means of improving quality of care is particularly relevant given the state of Canada's current health services. Canada's system is costly; in 2009, Canada's health spending (at over 11% of our Gross



Domestic Product) was higher on average than other developed countries world-wide (Organisation for Economic Co-operation and Development, 2011). Additionally, only 70.6% of spending on Canada's universal health care system was funded by public sources in 2009: a number that has decreased over the last 20 years, and will likely continue to drop (OECD, 2011). This means that the remainder is largely paid for by the private sector. At the same time, the services rendered by Canada's system do not always correspond with this expense. At a mere 2.4 physicians per 1000 people, we have fewer physicians per capita as compared to other developed nations (OECD, 2011); the percentage of Canadians who have a regular medical doctor has steadily decreased (Turcotte, 2011). With regard to health outcomes, while Canada is among the healthier countries in the world, there are huge health disparities that exist, particularly among racialized and socioeconomic groups (Evans, Hertzman, & Morgan, 2007). Genderbased inequalities are also evident, with women consistently reporting higher levels of mental health issues and chronic diseases (Denton, Prus, & Walters, 2004). In other words, Canada's current system might be failing a significant portion of its potential users, and unfortunately it is the perspectives of these marginalized groups that are largely missing.

Clearly, the roots of health inequalities are complex and interwoven; for example, differences in men's and women's health statuses and behaviours are mediated by other important vulnerabilities and social determinants, such as race and class (Denton et al., 2004). To focus a research project, one must make important decisions about which factors to study and populations to sample. The need to include patients' perspectives is essential; the difficulty is in narrowing down who the patient is, and whose perspective



that voice represents. For the purposes of this project, I chose to focus on *women's* perspectives of their health care. The main impetus for this choice is that women are the major consumers of health care, yet the practice of women's health care is held back by a lack of gender sensitive research and practice (Hoffman, Maraldo, Coons, & Johnson, 1997). In the remainder of this chapter, I will contextualize the need for research on women's voices in particular. This will involve several major components, including an outline of the current political context for the study of women's health in Canada; a discussion of the contributions of the Women's Health Movement to the study of women's health; a description of the theoretical approaches historically taken to explore women's health needs; an exploration of women's specific health care needs; a description of women centred care; and a description of the present study.

#### Women and the Canadian Health Care System

Making up slightly more than half of the Canadian population, women have historically suffered through centuries of systemic marginalization in relation to understandings of health and health research. It was only within the last several decades that we acknowledged the significance of gender in terms of health outcomes, and made women's health a national priority and research agenda (Correa-de-Araujo, 2004). Yet while we now purport to recognize that gender is an important determinant of health, in terms of the Canadian government's subsequent health care policies and funding, the response to this "recognition" has been disingenuous at best, and malevolent at worst. From 2009 to 2010, for example, Planned Parenthood went without a response in their requests for funding from the Canadian government (International Planned Parenthood Federation, 2010). Worse still, in 2012 the Conservative government announced that it



would cut the Women's Health Contribution Program (WHCP), a program that existed for almost two decades and was responsible for a significant amount of research activity related to women's health (Canadian Women's Health Network, 2012). The potential ramifications of these cuts are frightening; the WHCP provided support for at least six programs devoted to the research and dissemination of findings in women's health, including Le Réseau Québécois d'Action pour la Santé des Femmes (RQASF), the Canadian Women's Health Network (CWHN), the Atlantic Centre of Excellence for Women's Health (ACEWH), the British Columbia Centre of Excellence for Women's Health (BCCEWH), the Prairie Women's Health Centre of Excellence (PWHCE) and the National Network on Environments and Women's Health (NNEWH). Clearly, funding cuts of this nature make it difficult for women's programs and organizations to operate, and will impact research and the provision of care (Varcoe, Hankivsky, & Morrow, 2007).

Beyond these cutbacks, there are countless others like them being made both explicitly and implicitly to primary health care services directed at women. For example, Women's Health of London, a clinic in London, Ontario, closed in 2009 because of lack of funding (J. Tucker, personal communication, November 2009). More recently, plans have been made to deal with deficits in the Erie-St. Clair Local Health Integration Network (LHIN; a governing body that helps determine the health service priorities of Ontario regions) by making cuts to services for seniors (Fantoni, 2012). Because a majority of seniors are women, these cuts will make it difficult for elderly women to receive adequate in-home care. As a result of these cutbacks, it is becoming increasingly important to explore the health care experiences of Canadian women. Again, patient



perspectives can illuminate issues related to quality of care and utilization of health services; research that explores *any* patients' perceptions is valuable. To fully comprehend the consequences of what some see as the Canadian government "devaluing" women's health, however, it is essential to focus specifically on the perspectives and experiences of the women who access health services. In particular, we need to explore women's perceptions of health services aimed at women specifically in order to ensure the quality of these programs and safeguard against further cutbacks (or the potential of these programs to disappear completely). Research regarding women's perspectives on policy changes and health care ideologies is already scarce, and unfortunately, there are consistently fewer resources to undertake projects of this nature. As such, I sought to shed some light on how women understand and experience women's health centres, and how they engage with the entire health system as a result. To set the stage for this undertaking, I will detail how we have historically understood women's health and health care needs.

#### **Contributions of the Women's Health Movement**

In order to contextualize this research project and to illuminate the current backlash against women's health, it is essential to discuss the history of feminist contributions to the Women's Health Movement. This history helps us identify where our current understandings of women's health developed its foundations and saw its greatest transformations. The feminist movement is often understood in three waves, although this conception has been critiqued for its tendency to exclude important feminist work that occurred "in-between" these waves (Reinharz, 1992). While it is a convenient way to organize a timeline of feminist activity, the three wave conceptualization and subsequent



understandings of the Women's Health Movement are inherently superficial; much of the feminist work relating to the Women's Health Movement blurs the lines of these three waves and must be understood as a fluid and evolving process. As such, I will present the history of these contributions without this "three wave" distinction.

The nineteenth to early twentieth century saw feminists challenge political decision making and power, and focus on gaining the right of women's suffrage. This era was largely dominated by an agenda set by white, Christian, middle-upper class women; in Canada, significant efforts included promoting temperance and improving poor working conditions (Newman, 2006; Prentice, 1988). Ultimately, the concerns of this era's feminists were that women's bodies did not preclude them from participating in the political process, and rather women's roles as primary caregivers gave them particular expertise that was critical to political decision making (Morrow, 2007).

Female consumer health activists within this era lobbied for changes to health care; this first form of health care activism and advocacy was largely known as the Popular Health Movement (Marieskind, 1975; Nichols, 2000). It was a period that also saw an increased concern with the medicalization of the body, which had significant implications for how women's bodies, and the natural processes of them, were viewed and understood. Midwives in particular were targeted by the medical industry as dirty and unskilled, and the impact of this smear campaign in terms of women's health was considerable. Not only were women's lives endangered by the largely ill-prepared obstetricians who saw birth as a medical procedure rather than natural physiological process, but by the 1930s midwives had almost disappeared (Ehrenreich & English, 2005).



Another important feminist concern of the Popular Health Movement was reproductive rights (i.e., abortion and contraception). Through this era, policies and laws prohibiting abortion and contraception were supported by a faction of feminists, largely as a means of securing women's maternal roles and reproductive status (Jackson, Camacho, Freund, Bigby, Walcott-McQuigg, et al., 2001). By the early twentieth century, however, birth control activists like Margaret Sanger advocated for legal and safe contraception (Chesler, 1992), an important step towards the contemporary Women's Health Movement.

The next major contributions to women's health came in the early 1960s through the mid-1980s, and this era is largely where we recognize the launch of the contemporary Women's Health Movement (Hyde, 2008; Nichols, 2000). Although again dominated by white, middle-class, and heterosexual ideals, feminists of this time period were focused on issues of equality to end discrimination and giving a greater presence to minority women's concerns (Morrow, 2007). This era saw women reclaim their bodies and reproductive rights and help define the health care they desired (Jackson et al., 2001). In the late 1970s, the Reproductive Rights National Network outlined 12 essential principles that defined the efforts of the Movement, including the right to contraception, abortion, and quality health care, among others (Reproductive Rights National Network, 1978). In addition to other key women's health issues of this era, such as violence against women and sexuality, these landmark principles have largely retained their relevancy to the current concerns of the Women's Health Movement (Hyde, 2008).

The efforts of feminists in this era to promote these principles and secure information about women's health were rewarded with the establishment of several



crucial health initiatives. The right to safe abortions, for example, was supported by the landmark 1973 Roe v. Wade decision of the Supreme Court of the United States to legalize abortion (Weisman, 1998). Although an American ruling, the Supreme Court of Canada used the decision in support of its own similar case in 1988, R. v. Morgentaler (Morgentaler, 1998). New advocacy programs and women's organizations related to health, such as the Vancouver Women's Health Collective (Kleiber & Light, 1978) and Planned Parenthood represented important responses to critiques of health care. Information about women's health, meanwhile, was shared through landmark journals, magazines, and other literature, such as *HealthSharing* magazine, the *Birth Control Handbook* (McGill University's Birth Control Committee, 1968), and *Our Bodies, Ourselves* (Boston Women's Health Collective, 1973). These initiatives signified an important challenge to medical authority (Boscoe, Basen, Alleyne, Bourrier-Lacroix, & White, 2004; Hyde, 2008; Morrow, 2007).

The last major contributions to the Women's Health Movement through the 1980s and 90s and up to today have been characterized by a postmodern analysis of our understanding of "women" and the social construction of our identities. In an age of internationalization and globalization, minority women's long standing critiques of colonialism finally reached the forefront of Canadian research (Morrow, 2007). Here, the scope of the Women's Health Movement broadened to include sexually transmitted illnesses, health needs of lesbians, minority women, and women experiencing poverty, among other diverse issues (Hyde, 2008; Weisman, 1998). This era was characterized by an advocacy agenda with women in key leadership positions in health care institutions, controlling legislative activity to develop women's health research and policy (Boscoe et



al., 2004). The Women's Health Contribution Program and Centres of Excellence for Women's Health Program were formed in 1996 to advance the health of women in Canada. Beyond conducting essential research on women's health, initiatives like these saw three major issues come to fruition: health care restructuring and reform, health as a global issue, and women centred care models (Morrow, 2007).

Based on the contributions of feminist activists over the past two centuries, our understanding of women's health has evolved greatly. While I have laid out significant feminist contributions as they concern the Women's Health Movement specifically, I have not discussed the fundamental assumptions underlying these efforts. Although the activities of the Women's Health Movement have influenced our current understanding of "women's health," the area as a field of study has at times been subjected to deficient methodologies and theoretical substructures, ensuring that our understanding of women's health topics is not always adequate. Next, I will discuss several approaches to studying women's health as a means of further contextualizing the need for research.

#### **Approaches to Understanding Women's Health**

Today, we define "women's health" according to several factors. We acknowledge the reality that women have diverse needs throughout their lifespan and that these needs are not just physical, but psychological and social (Donoghue, 1996; Fogel & Woods, 1995). We recognize the fact that women's needs differ from men's, and emphasize that women need to be involved in decision making about their bodies (Donoghue, 1996). However, this definition evolved over time (and is continuing to evolve) based on the various theoretical and methodological approaches we have undertaken in research and practice. In general, research and policy have been informed



by four major approaches to understanding women's health: the gender neutral approach, biological and reproductive determinism, gender and sex analysis, and intersectionality (Varcoe, et al., 2007).

The first approach, gender neutrality, was epitomized by sex and gender not being taken into account. Rather, this aspect of a person's identity was seen as unrelated to health concerns. This approach allowed health research and policy to neglect and exclude women's experiences, ensuring that women's health needs were not met (Hills & Mullett, 2002; 2005). For example, cardiovascular disease (CVD), though afflicting women and men at comparable rates, was largely understood by researchers and clinicians as a "male" disease and was thus dominated by clinical trials with men only (National Institutes of Health, 1995; Young, 2007). Unfortunately, further research showed that the symptoms associated with CVD differed for men and women (Society for Women's Health Research, 2011). In many cases then, women suffering from CVD went undiagnosed, which placed them at increased risk for mortality.

The second approach, meanwhile, was characterized by biological and reproduction determinism. Here, the focus was placed on reproductive physiology as it differentiated women from men. Under this approach, research related to women's health was similarly narrow in scope and served to perpetuate negative stereotypes and pathologize women's natural bodily processes, such as menstrual cycle changes and menopause (Chrisler & Levy, 1990; Donner & Pederson, 2004).

The third approach, gender and sex analysis, was first championed in the 1970s (Williams, 1999). This type of analysis was seen as a means of identifying differences in experiences and inequalities between men and women, and it was quickly adopted by the



Canadian International Development Agency and later the Canadian government to inform federal policy (Grant, 2002). Although sex and gender represent two very different constructs (i.e., biological factors in the case of the former, and socio-cultural factors in the latter), the two are often conflated. For example, Health Canada does not make a distinction between the two as separate contributors to health, instead maintaining a commitment to "sex and gender-based analysis" (Health Canada, 2009).

Practically speaking, commitments to this type of analysis did not result in a significant change in the actual occurrence of analyses conducted by sex, and even less so by gender (Stewart, Cheung, Layne, & Evis, 2000). On a theoretical level, gender and sex analysis has also been critiqued. What this analysis ultimately encouraged was an inclusion of social determinants of health (and not just biological ones). As such, employing a gender and sex analysis should also allow us to acknowledge that other important social determinants of health, such as class or race, influence women's health (Correa-de-Araujo, 2004; Weisman, 1997). Analyses on determinants of health, however, are generally conducted in isolation. The impacts of these factors on health are largely considered separately, which homogenizes the experiences of "women" and ignores differences that cut across gender. Furthermore, when combined, these factors are considered additive; a Black woman's experiences of marginalization can then purportedly be understood by considering the effects of racism and sexism separately. However, these experiences are interrelated, and represent inseparable social divisions; additive analyses, then, limit our understandings of how the multiple aspects of our identity interact (Spelman, 1988).



In response to the limitations of gender and sex analysis, multiracial feminists played a crucial role in advocating for a fourth approach that would explore such intersecting hierarchies. Eventually coined "intersectionality" (Crenshaw, 1989; 1991), the groundwork for this approach was laid out previously by several scholars (see hooks, 1984; or Spelman, 1988; among others). Under this approach, sex and gender are seen as inseparable from other forms of social difference, such as race, ethnicity, Indigeneity, gender, class, sexuality, geography, age, ability, immigration status, and religion (Weber & Parra-Medina, 2003). In other words, we finally come to acknowledge the many differences *among* women (Hankivsky & Cormier, 2009; Varcoe et al., 2007). Because intersectionality represents the most inclusive approach to studying women's health, it is the approach that I used as a framework for my analysis and recommendations.

Using intersectionality, the relationships between dimensions of social identity and difference are not just embraced, they are recognized as a central analytical category (McCall, 2005). Relatively speaking, there has been little theory generated about "intersectionality" itself (Carter, Sellers, & Squires, 2002), yet the influence of its theoretical underpinnings have been profound. For example, as a result of the work of women like hooks, Spelman, and Crenshaw, researchers have increasingly sought to avoid essentializing men and women, incorporate multicultural sensitivity into research activities, and acknowledge Western bias (Lorber, 2006). In other words, it has changed how we think about social structures and oppression (Sigle-Rushton & Perrons, 2007).

Ultimately, intersectionality requires more than just thinking about these constructs, and instead must incorporate methodologies for applying the paradigm in research (Harding & Norberg, 2005). Generally, it is accepted that each category of social



difference is mutually transformative rather than independent (Glenn, 1999). Although there is currently no straightforward way to manage the complexity of such an analysis, intersectional approaches are generally grounded in lived experiences to provide a basis for the pursuit of social justice (Hankivsky & Cormier, 2009). In the next chapter, I will briefly detail the methodological concerns associated with intersectionality and discuss the qualitative approach I employed in my analysis.

These four approaches to understanding women's health (i.e., gender neutrality, biological and reproductive determinism, gender and sex analysis, and intersectionality) represent an evolution in thinking. The fact that conceptualizations of women's health and associated research have changed and are changing, however, does not necessarily mean that outcomes associated with these changes have been truly evident. All four of these approaches to women's health still exist in some form, ensuring that our understandings of women's health issues are not as comprehensive as they could be. In the next section, I will detail some of the important findings yielded from the last two approaches to research on women's health and health care needs.

#### Women's Health Needs

Trying to report on intersectional findings regarding women's health is difficult; again, most approaches looking at multiple aspects of a woman's identity have used gender and sex analysis and then taken an additive approach rather than a truly intersectional one. However, there is some acknowledgement that multiple determinants of health have an impact on women. I will start with findings from gender and sex analysis (as this latter approach is the most common and has generated the most research) and then discuss multiple determinants of health.



Because much of the research from the last couple of decades has used gender and sex analysis as a framework, it is not surprising that women's health needs are often talked about in relation to how they differ from men. Such work has indicated that women often experience and report worse health than men, but that explaining this difference is complex (Denton et al., 2004; McDonough & Walters, 2001). Namely, Canadian men experience higher rates of mortality, but Canadian women report higher levels of mental health issues and chronic diseases, and have higher life expectancy (Turcotte, 2011).

Access to services and health care utilization also differ according to gender. For example, women are more frequent users of the health care system than men (Turcotte, 2011); this is largely due to the fact that women live longer than men, have higher rates of chronic disease, and are more likely to give care and look after children (Hills & Mullett, 2002). Women are also more likely than men to have a general practitioner, more likely to try to find one, and if they do not have a doctor, are more likely to state that there was no doctor in their area as a reason (Turcotte, 2011). However, important disparities exist within women's access to health services across Canada. Aboriginal and impoverished women, for example, are over-represented in groups of women who have never had a pap test (Colman, 2003).

With regard to what women want out of their services, they tend to take a different approach to their health care than men; women are more inclined than men to desire a caring and collaborative doctor-patient relationship and respect for their own experiences, and prefer an active role in the decision making process (Bean-Mayberry et al., 2003; Bottorff, Balneaves, Sent, Grewel, & Browne, 2001). This difference in how



women expect to receive care is reflected in the greater percentage of women who change physicians due to dissatisfaction with their care (Bean-Mayberry et al., 2003; Colman, 2003). However, disparities in access and utilization of services exist across Canada, and for Ontario specifically, the greatest disparities occur for women in rural and northern Ontario locations (Tepper, Schultz, Rothwell, & Chan, 2005). As such, it is highly probable that not all women's voices are represented in these particular "desires" that have been identified in the literature.

Along this vein, research indicates that for certain populations of women, such as Aboriginal and other minority women, single mothers, unattached elderly women, unemployed women, among others, there are groups of indicators that lead to the experience of vulnerability (Colman, 2003). For example, lack of education and adequate housing, and political powerlessness are important factors associated with social exclusion. Having lower socioeconomic status contributes greatly to this cluster of disadvantages (Colman, 2003).

Other research has explored how lifestyle and psychosocial factors influencing health (such as health habits and behaviours) are gendered. Two hypotheses in particular are relevant to understanding sex- and gender-related factors as they relate to other determinants of health: the differential exposure hypothesis, and the differential vulnerability hypothesis (Denton et al., 2004). The differential exposure hypothesis states that women will report more health problems because they are exposed to different structural, behavioural, and psychosocial determinants of health than men. For example, women tend to have lower incomes, experience more stressful life events, and have greater demands in their social roles (Arber & Cooper, 1999; McDonough & Walters,



2001). However, men are less likely to use health services to begin with (Bertakis et al., 2000). The differential vulnerability hypothesis, meanwhile, states that women report more health problems because they respond differently than men to the same determinants of health (McDonough & Walters, 2001). For example, higher income and social support are more important predictors of health for women than men, and women respond differently to daily stressors than men do (Denton et al., 2004).

Research has shown that when controlling for exposure to social, behavioural, and structural factors, gender differences in health reporting remain (Bertakis et al, 2000; Denton et al., 2004); this may mean that the differential exposure hypothesis alone is inadequate to explain gendered differences in health. When exploring how people respond to and deal with structural, behavioural, and psychosocial determinants of health, important differences continue to exist by gender. For example, research has shown that age, family structure, education, income, occupation, and social support are all factors that differ by gender (Denton et al., 2004). It thus appears that women do also confront the same resources and challenges differently than men, and access health services differently as well.

One positive outcome as a result of research conducted using gender and sex analysis is that there has been an attempt to place women at the centre of their care needs and create a new health service delivery option in "women centred care" (Hoffman et al., 1997). By promoting ideals that are women centred, health care researchers, providers, policy makers, and patients alike acknowledge that women are the major consumers of health care and that women's health issues are important. They further recognize that the practice of women's health care is held back by a lack of gender sensitive research and



practice, and that the fragmentation of women's services disregards issues of accessibility and accountability (Hoffman et al., 1997). Because women centred care signifies one major way that researchers and policy makers attempted to address women's primary health needs specifically, this approach represents the base modality through which I attempted to gain women's perspectives of services directed *at women*. That is, I wanted to talk to women who had experienced women centred care in particular. In the next section I will define women centred care and attempt to differentiate it from other similar models of health care.

## **Women Centred Care**

Women centred care was borne largely out of findings from the third approach to understanding women's health, and has thus been critiqued for its tendency to focus on sex and gender at the expense of the differences between women, such as race, ethnicity, culture, class, and sexual orientation (Morrow, 2007). Although this model of care was developed out of gender and sex analysis, it does not mean that the care itself does not examine the intersections of multiple determinants of health. A brief review of literature regarding the foundations and principles of women centred care will illustrate that conceptually, women centred care is concerned with all aspects of a woman's social identity and the issues associated with these characteristics.

**Conceptual definitions.** A clear definition of women centred care is difficult to obtain (Barnett, White, & Horne, 2002); currently there are several different working models of women centred care across Canada and the U.S., including the National Centres of Excellence in Women's Health (NCEWH; both American and Canadian), the Vancouver/Richmond Health Board's Framework for Women centred Care (VRHB,



2001), and the Women's Health Clinic in Winnipeg (WHCW; Horne, Donner, & Thurston, 1999). Hoffman and colleagues (1997) proposed that women centred care is a sex and gender informed practice that focuses holistically on the woman in diverse contexts of her life. They suggested that an integrative and team approach should be taken, where multiple care providers (i.e., nurse practitioner, physician, mental health provider) would work in tandem to meet women's needs, including risk identification, screening, prevention, treatment, disease management, consultation, and biobehavioural and psychosocial issues (Hoffman et al., 1997). Further aspects of the women centred mandate have been proposed by Barnett and colleagues (2002), including promoting empowerment and respect, taking into consideration other complexities of women's lives (e.g., physical, social, emotional, psychological, socioeconomical, cultural), and endorsing women-based research and a collaborative work environment. Other researchers have focused on establishing innovation and resources, emphasizing autonomy and peer support, appropriate health promotion and education for women, and access to women practitioners as critical to the women centred process (Boscoe et al., 2004). Based on these various definitions, which carry similar values and goals, there appears to be two major ways to apply a women centred approach: through research and advocacy, and through primary care. For example, the NCEWH primarily functions to conduct research and inform policy. On the other hand, the WHCW is a clinic that offers primary care. Notably, both of these services consider themselves "women centred."

As an important step to finalizing a comprehensive set of guiding principles for women centred care in Canada, Hills and Mullett (2002) used a co-operative inquiry approach to collaborate with professional associations for nurses, naturopaths, dieticians,



nutritionists, physicians and surgeons, counsellors, homeopaths, dentists, midwives, and other health or medical groups in order to define women centred care. Based on this multi-phase research, the British Columbia Minister of Health endorsed an inclusive set of women centred principles proposed by this working group (Hills & Mullett, 2005). According to these principles, women centred health care must: a) treat women with respect and acknowledge their experiences, b) recognize and accept that women are diverse with regard to physiological, ethnic, economic, sexual orientation, ability, cultural, religious, and educational factors, c) acknowledge women as the primary caregivers and child rearers in our society, and that this fact often leads to greater difficulty in accessing health care, d) explore and consider the impact of social, economic, societal, and environmental factors, and recognize societal and cultural gender imbalances, e) give women information to make informed choices, and give them the right to ask questions and to consider appropriate medical or health alternatives, f) allow for the cooperation with mutually supportive health professionals and allow for collaboration, and continuity and quality of care, g) allow for self-determination, and h) consider contributions of other health care providers (Hills & Mullett, 2002, 2005).

While women centred care as a concept developed out of sex and gender analysis, Hills and Mullett's (2002; 2005) comprehensive and inclusive definition appears to also be intersectional in nature; it acknowledges that women are different from one another and that all forms of social identity and difference are critical to the understanding of women's health needs. However, this particular definition and body of research was conducted entirely in British Columbia, an acknowledged front-runner in Canadian policy and health reform for women. Across the rest of Canada, women's needs and



perspectives are largely absent from research related to Canadian health care reform (Donner & Pederson, 2004), and again clear definitions of women centred care are hard to obtain. In particular, Ontario does not have a Centre of Excellence for Women's Health (though it is home to the related National Network on Environments and Women's Health and Ontario Women's Health Network), and this may have had an impact on the lack of clarity on women centred models in this province.

Beyond the lack of clarity in definitions of women centred care in Ontario (and whether the term is applied at policy or primary care level, or both), there are several other issues that must be addressed. If women centred care is being applied at the primary care level, does that mean that all women's health centres are "women centred" as Hills and Mullet have defined the term? The impetus for the "women's health centre" also arose out of gender and sex analysis, and these facilities have been described in the literature as the "future" of the Women's Health Movement (Nichols, 2000). If there is a difference between a facility that operates solely for women and "women centred care," these factors must be addressed.

In addition to the question of how women centred care differs from a women's health centre is the question of whether women centred care as a paradigm is qualitatively different from other models of care defined in the medical literature. For example, there have been concerns that women centred care is not justifiably different from patient centred care. There also appears to be a movement in women's health units in Ontario hospitals to focus on family centred care (e.g., the Women's Program at London Health Sciences Centre and the Grey Bruce Health Services Women and Child Care Unit). Furthermore, women centred care is commonly used interchangeably with *woman* 



centred care, a concept from the midwifery literature. Lastly, it is possible that centres may adhere to women centred principles, but not identify in this manner at all. In order to justify the inclusion of women centred care in my research (i.e., as the model of care with which I wanted to explore women's perceptions), it is thus critical to discern whether, and how, women centred care is different from other models of primary care.

**Women's health centres.** As I have already mentioned, women's health centres emerged as an important development of the Women's Health Movement and the understanding that women needed specific types of services (Kuhlmann, 2009; Nichols, 2000). It is often difficult to see the difference between women's health centres and women centered care. The terms have been used interchangeably, and some scholars appear to assume that any women's health centre is women centred (for example, see Kuhlmann, 2009; Peters, 2010; or Weisman, Curbow, & Khoury, 1995), without considering the principles from which the centre operates or the purpose of the centre's particular existence (e.g., solely a sexual health clinic). Yet, in the Canadian literature at least, there has been some effort to differentiate women's centres from women centred care. According to Boscoe and colleagues, women centred care is more than just "pink walls or even 'nicer' female doctors' (2004, p. 8); it is an approach that listens to women's voices and puts women at the centre of their needs. Additionally, in the 1990s when women's health centres were emerging at a rapid pace, researchers identified several types of women's health centres. For example, women's health centres were sometimes noted to have a single focus, like breast cancer or alcohol addiction. Some centres also had a predominantly reproductive focus, such as sexual health and birthing centres. Lastly, women's health centres were identified as being holistic or feminist in



focus (Lundy & Mason, 1994), which would seemingly most closely represent the women centred mandate identified by Hills and Mullett.

It appears that while related, women's health centres and women centred care are different constructs, and that the difference might lie in the full spectrum of services rendered by each. That is, women centred care cannot only be applied at the patient level, but it is a theoretical approach that also allows for the development of other activities, programs, research, and services (Boscoe et al., 2004). Women's health centres, meanwhile, only provide primary care, and *can* fall under the larger approach of women centred care. Because this distinction is somewhat unclear within the literature, I chose to be pragmatic in my methodological approach to studying women centred care, as I will outline later in this chapter and the next. Before I do that, however, it is important to further differentiate women centred care from patient, family, and woman centred care.

Patient centred care. Patient centred care is an approach to primary health care that is similar on many levels to women centred care. In fact, patient centred approaches were initially advocated for within the Women's Health Movement as a means of reclaiming the rights of patients (Kuhlmann, 2009). Originally developed to enhance the capacity of patients for self-care by moving out of hospitals and into the patients' communities (Smith, 2006), it is a model of care that seeks to place the patient at the centre of their needs. Many definitions have been applied to this process, with more than 14 definitional components proposed over the last four decades. Most critical to the movement have been Stewart (1995), and Mead and Bower's (2000) conceptualizations of patient centred care, which have endorsed principles of care including finding common ground or partnership between the doctor and patient, understanding the patient as a



whole person, acknowledging the patient's perspective, and allowing for patient control in decision making, among other principles. Ultimately, patient centred care is defined in separate parts to make sense of the whole process, but should be understood as a holistic concept (Stewart, 2001).

While patient centred care is one of the most commonly used terms in today's medical field, it is actually one of the least understood (Stewart, 2001). Almost every health care provider purports to be "patient centred" and cites any number of the proposed definitions in support of this claim. Unfortunately, there is little to no empirical support to suggest that any of these definitions actually matter to patients (Little et al., 2001). Patient perspectives are rarely sought, and the relationship between patient centred care and improved patient outcomes (i.e., the key markers in medicine for inclusion in public policy) is conflicted at best. A recent systematic review (see Wolfe, 2008) of this relationship found that the only patient reported outcome regularly improved by patient centred care was satisfaction with care which, as I have previously detailed, is often a problematic construct.

Some of the principles of patient centred care appear to coincide with those of women centred care, such as putting the patient (i.e., woman) and her needs first, respecting the patient (i.e., woman) and her perspective, or involving the patient (i.e., woman) in the decision making process. The difference between them, however, is clear; only women centred care specifically acknowledges the imbalances in health care related to gender, and seeks to place a woman at the centre of her needs. Another important difference is that women centred care, as defined by Hills and Mullet, takes into account



all forms of social difference, while patient centred care does not explicitly call for such an analysis.

Beyond these differences, there are commonalities to patient centred and women centred care when it comes to the bodies of literature associated with the two constructs. As previously mentioned, there is little in the way of research regarding patient perspectives of patient centred care; patients' voices and concerns are almost never heard, while practitioner's opinions have made up the bulk of the research. While women's perspectives and understandings of women centred care are also largely missing, it is not necessarily that this has come at the expense of studying providers' perspectives only. As Bensing (2000) notes, the ideological base for patient centred care is better developed than its evidence base, and this is even more true for women centred care (i.e., the analysis simply has not been done yet). To summarize, the theoretical frameworks from which patient centred care and women centred care were developed are similar but appear to be distinct in important ways.

**Family centred care.** In Ontario, there appears to have been a movement towards using the terminology "family centred," particularly in women's health units housed in hospitals. Two prominent examples include the Women's Program at London Health Sciences Centre and the Grey Bruce Health Services Women and Child Care Unit. Family centred care is often understood as a philosophy that acknowledges and respects the role that family has in the lives of children with health care needs (Caty, Laroque, & Koren, 2001). That is, it places the child, in the context of his or her family, at the centre of care (MacKean, Thurston, & Scott, 2005). Family centred care largely developed out of the needs of parents of young children with chronic diseases (MacKean et al., 2005),



and as such it is an approach that embraces the principles of respect, choice, collaboration, and empowerment (Institute for Patient and Family Centered Care, 2012). These principles are similar to those that guide women centred care.

Although family centred language appears to be gaining ground in Ontario, it is important to contextualize this growth. Women's health units in hospitals often explicitly include children within their services, such as the case with Grey Bruce. Because these facilities also treat children, there is a need for a family centred mandate. This approach acknowledges the disproportionate burden that women carry as primary caregivers (Scott, Horne, & Thurston, 2000), such that women will often have their children with them during health care visits and are more likely to be impacted financially by a sick child; these factors would make the approach relevant to women's health centres. Other areas of women's health care provision, such as the addictions sector, have followed suit. There has been a movement toward making treatment "gender responsive" (Covington, 2001) so that women are treated with their children (Worley, Conners, Crone, Williams, & Bokony, 2005). However, there has been some indication that a family centred mandate, at least in terms of maternity care, might work against empowering women specifically, and that a shift to placing the focus back on the woman giving birth is more appropriate (Midmer, 1992).

Because the term "family centred" is currently used in Ontario women's health facilities, it is an important construct to consider for this project. It is evident, however, that family and women centred care vary in one major way; family centred care places the child at the centre, while women centred care places the woman at the centre of her health needs.



Woman centred care: The case of midwifery. The last construct I would like to distinguish women centred care from is woman centred care, a midwifery concept that is at least phonetically similar to women centred care. Woman centred care is specific to pregnancy and the birthing process, and involves putting emphasis on a woman's own beliefs and rights about her pregnancy and birth, her right to make informed choices in this process, and maternal autonomy (Reid, Hallan, & McGuire, 1998). In addition, woman centred care encompasses the baby and family's needs, bridges the multitude of settings a woman comes across in her pregnancy, and addresses social, emotional, physical, psychological, spiritual, and cultural needs (Leap, 2000). This model of care is an alternative to the traditional model that is governed by paternalistic values and gives a woman little control in her pregnancy. Midwives have suggested that labour and birth can be disempowering and over-medicalized within the traditional paradigm of care, and that midwifery is a woman centred alternative to this often negative process. As a result, woman centred care should be understood as a philosophy that underpins all care given by midwives, and is related to pregnancy, birth, and the puerperium (Reid, 1997).

There are similarities between women and woman centred care regardless of their different meanings. Both arose out of the Women's Health Movement and the call to improve services offered to women through the employment of feminist ethics (Leap, 2009). There are also theoretical similarities; both attempt to address issues of social difference, focus on a woman's particular needs, and recognize the need for choice. Leap (2009) noted that within the midwifery literature, women and woman centred care are often used interchangeably to the detriment of the field. She suggests that to use the term women centred care when discussing midwifery is to "water down the role of midwives



in providing individualized care to a particular woman" (p. 13). Women centred should then only be the term applied to the general approach of health care.

Women centred care is a paradigm of care that has been differentiated in the literature from patient, family, and woman centred care. Less clearly, it can also be differentiated from the concept of a women's health centre. The issue now remains to fully articulate why I chose women centred care as the vehicle to explore women's perceptions rather than any of these other modes of health care.

Implications of women centred care. Studies have shown that there should and can be great benefits for women centred care, including meeting women's needs because women were part of the process (Barnett et al., 2002) and the improvement of comprehensiveness and continuity of services (Weisman & Squires, 2000). However, this area of research is plagued by inconsistencies (Hills & Mullett, 2005). Some reports have indicated that women utilizing this care are more satisfied with their services, and yet others have found no such distinction (Hills & Mullett, 2005). It has also been suggested that the traditional medical model is more effective at delivering preventative care (Phelan, Burke, Deyo, Koepsell, & LaCroix, 2000).

One issue is that there has not been a uniform philosophy of care applied to research related to women centred care. Two groups of researchers (i.e., Hills & Mullett, 2002; 2005 and Barnett et al., 2002) have worked to create multidisciplinary and inclusive definitions, however other conceptualizations of women centred care are not completely formed. For example, as I previously detailed, there is very little research that systematically differentiates women centred care from women's health centres; this leaves room to question if a difference, in fact, exists between these two constructs.



Ultimately, it is likely that no single health centre can incorporate every aspect of each women centred model due to differing contextual factors (Barnett et al., 2002). For example, an explicit agenda related to cultural competency may be much more salient for health centres dealing with large urban populations or predominantly aboriginal populations. It is possible, however, to arrive at a better understanding of how these general foundational principles of women centred care affect the women they serve, and to use women's health centres as a place to start examining these principles.

The need for research. Based on preliminary work revealing multiple benefits of women centred health care, it is evident that further research in this area is not only relevant, it is essential (Correa-de-Araujo, 2004; Hills & Mullett, 2005). Women's perceptions of women's health centres are needed to undertake an evaluation of women centred practices. Such evaluations are imperative to understand the quality of services, issues in accessibility, and whether or not women's health centres are inherently "women centred." A major goal of women centred care is to increasingly improve the status of women's health in Canada to include a vision of health beyond pure physical, and largely reproductive, focuses; we need to evaluate whether this goal is being met by seeking women's experiences and perspectives of this care.

As I have already detailed, research related to women's health and women centred care is also imperative given the current state of Canada's health care services and funding practices related to women's health. That is, women's health centres are at risk for losing their funding, and there are also issues related to regional availability of health services for women (Tepper et al., 2005). Another important application of this research is to help build a body of literature that will inform future policies about this type of care;



we need to expand on the Women's Health Movement that has seen great momentum yet is facing a backlash at the policy/funding level. Women centred care was only identified as a primary area of concern in the last two decades (Morrow, 2007), and programs of this nature are already disappearing. Unfortunately, a lack of resources, funding, genderspecific research tools, and intersectional analysis have ensured that this critical evaluation has not been conducted (Donner & Pederson, 2004; Hills & Mullett, 2005).

## **The Present Study**

In this study I attempted to fill some of the gaps in the literature on women's health care. Namely, I wanted to contribute to differentiating women centred care from women's health centres; add to the body of literature on women's perspectives of their health care (beyond satisfaction); and employ an intersectional analysis, as researchers have long called for. To meet these larger goals, I explored women's perceptions of women centred care in the context of Ontario women's health centres offering primary care. This study was grounded in Hills and Mullett's (2002; 2005) proposed guiding principles for women centred care; I used these principles as a standard to explore whether or not, and how, women centred care was employed in Ontario and experienced by women at women's health centres.

**Purpose and research questions.** I had two general purposes to this project. My first purpose was to explore understandings of women centred care in Ontario to identify working models of this care in our province and add to the literature differentiating women centred care from women's health centres (if a difference existed). My second purpose was to provide an in-depth exploration of women's perceptions of women's health centres to reveal their understandings of women centred care and to provide



insight into their experiences of their own health and health needs within this paradigm of care. The research questions that guided my exploratory analysis thus included:

- How is the women centred mandate (as defined by Hill and Mullett) being applied in Ontario women's health centres offering primary care? How do women's health centres classify themselves (i.e., is the term "women centred" even applicable in Ontario)?
- 2. Why do women initially choose a women's health centre, and what does this have to do with the construct of women centred care? Why do women continue to use a women's health centre?
- 3. How do women describe their experiences with women's health centres and women centred care? What meaning do they give to the women centred mandate and how has a women's health centre informed their understandings of their own health needs?



#### CHAPTER II

#### Methodology

In this chapter I will outline the qualitative methodology employed in this study, including the feminist and intersectional frameworks I used for the overall project. Following this discussion of the philosophical underpinnings of my research, I will present a reflexive discussion of the challenges I faced in this research process as a way of contextualizing my eventual work. Finally, I will discuss the two phases of this research project, including the participants, methods, and data analysis of phase one, and participants, methods, and Interpretative Phenomenological Analysis (IPA) of phase two. I will conclude by describing evaluative criteria and ethical considerations for my research.

### **Qualitative Methodology**

Qualitative research is broadly construed as having interest in meaning and how people make sense of and experience the world (Creswell, 1998), and was the most appropriate means of answering my research questions related to how women have experienced women centred care. Although I will elaborate on my methods in a later section of this chapter, I would like to first note that I employed both little q and Big Q methods (Kidder & Fine, 1987) in undertaking this project. I mention this methods related issue in this opening paragraph, rather than later in the chapter where the rest of the methods are described, because it highlights my epistemological beliefs about how research should be conducted. Small q methods are those that involve a non-numerical data collection technique (such as an open-ended survey) used within a hypotheticodeductivist design (Willig, 2007). Big Q methods, in contrast, are open-ended, inductive,



concerned with exploring participant defined meaning, and include interviews or focus groups (Willig, 2007). Within the qualitative research community, there are many opinions concerning whether small q methods can actually be considered qualitative research. Purists regard small q methods as quantitative because the process involves a narrowly specified agenda and hypothetico-deductivist design (Lofland & Lofland, 1995), and as such may consider this approach to research as incongruent with a true qualitative study. While I do believe small q methods to be quantitative in nature, I believed that this quantitative approach was crucial to my research and thus congruent with my "worldview" and research values. I saw myself as a pragmatist rather than a purist, and sought appropriate and workable solutions to my research problems, in line with what is largely considered a mixed methods study (Johnson & Onwuegbuzie, 2004).

### **Feminist Framework**

The larger framework that informed my research was feminist, as it is the only approach that takes into account a women centred viewpoint as its foundation and seeks to replace androcentric values and policies with gynocentric ones (Klima, 2001). To employ a feminist framework, I saw this research as *for* women, and not about women, and focused on the lived experiences of my participants (Reinharz, 1992). I wanted to capture their narratives and identities in a way that would reveal important strengths and shortcomings in Ontario's approach to women centred health care, but would also tell the women's stories in a "credible" way. I was committed to letting the women guide the interview process and talk about anything they saw as relevant to this topic so that my personal agenda did not overshadow the issues they deemed most important.



Feminist studies must be concerned with issues of difference and the question of social power, must be resistant to scientific oppression, and be committed to political activism and social justice (Ironstone-Catterall et al., 1998). To meet these basic requirements, I undertook an intersectional analysis. Again, intersectionality not only embraces the relationships between different dimensions of social identity and difference, it puts them as a central analytical category (McCall, 2005), making this approach congruent with a feminist framework. I also had a larger goal of uncovering themes that would "give voice" to women who had not been heard. Before I committed to this goal, I critically examined my perspective that I could possibly "give voice" to my participants. "Giving voice" is generally seen as one of the most vital components of the feminist movement (Ashby, 2011; DeVault, 1999) and has played a crucial role in defining qualitative research as a whole despite the fact that it is an approach that tends to go unchallenged. Recently it has been argued that it is a practice that potentially reinforces the systems of oppression it is trying to overcome, and that "giving voice" to someone else re-establishes hierarchies of power and privilege (Ashby, 2011). Even though I have assumed that the women in my study "needed" someone else to tell their stories, I have chosen to reframe my perspective as seeing the women as fully capable of exercising their own voices. Unfortunately, they have rarely been asked to do so and instead have been systematically suppressed by the Ontario health care system. One of the key ways that I attempted to redress these assumptions of "giving voice" was to locate contradictions in my analysis, and on occasion reconsider how I presented the women's stories. At times, I found my own perspective creeping into the analysis. Because I wanted to present the women's perspectives as free from my biases as possible, I often



33

had to re-write sections of my analysis. By critically examining and redressing the fundamental assumptions associated with "giving voice" I believe I have effectively committed my position to the pursuit of social justice.

Finally, feminist work supports the notion that knowledge is socially constructed; here, human experience is understood as being mediated by history, culture, and linguistics, and it is recognized that there are multiple "knowledges" as opposed to one knowledge (Burr, 1995). I readily acknowledge that a multitude of interpretations could have been applied to this data. The final research design and analysis were also emergent; they evolved and changed as the study progressed. Finally, my values and biases were continually acknowledged, and transparency and reflexivity (i.e., acknowledging my contributions to this process) were imperative at each step of the research. As aforementioned, I had to continually reconsider how I presented my participants' perspectives in order to not appear judgmental and to remove myself from their experiences as much as possible.

#### Intersectionality

For health research to be considered intersectional, it should incorporate the perspective at every stage: from the point that we formulate a research question (i.e., decide whose perspectives we want to address) and conduct the literature review (i.e., ensure that it is interdisciplinary), to the research design and dissemination of our results to all relevant stakeholders, including participants (Hankivsky & Cormier, 2009; Morris & Bunjun, 2007). As such, it is best thought of as its own paradigm or theoretical framework for research rather a form of simple analysis (Hankivsky & Cormier, 2009). Although there is little in the way of recommendations for researchers who wish to carry



out intersectional projects (Carter, Sellers, & Squires, 2002; Taylor, 2009), most cues that do exist are taken from the feminist literature. For example, feminist scholars have identified that the approach does not require devising new *methods* for studying social phenomena, and rather, it is a research (and policy) paradigm that changes the way we *think about and understand* social problems (Hancock, 2007). I would like to focus on the contributions of intersectionality to how I approached my research design and data analysis because these are most relevant to my methodology chapter.

According to Hankivsky and Cormier (2009), one of the most essential aspects of intersectional analysis in terms of women's health is to circumvent using singular categories (e.g., trying to group all women's experiences together solely on gender), and explore other aspects of identities that may contribute to experiences of marginalization and disadvantage. Several researchers have suggested that the case study approach is an appropriate means to address this issue (McCall, 2005; Valentine, 2007). Case studies are founded on individual experience, and can lead to an attempt to infer larger social implications based on these experiences (Taylor, 2009). In the end, I explored multiple "cases" in their own rights, and attempted to move to more general claims in a narrative account that included detailed, individualized information from each participant's story (i.e., an analysis of narratives; Polkinghorne, 1995). To do so, I collected women's narratives through interviews that explored their experiences, and situated them within the perspectives of these particular women (McCall, 2005). Again, this is not a *new* method, but this particular process of data collection (and analysis) has helped to define the field of intersectionality (McCall, 2005).



With regard to my analysis of these narratives, I used an approach that explores "categories of difference" (Dhamoon, 2008 as cited in Hankivsky & Cormier, 2009). According to McCall (2005), this process can generally be understood as falling along a spectrum. On one end of the spectrum is an approach called anticategorical complexity; here researchers would deconstruct categories (such as gender, class, sexual orientation), seeing them as too simplistic and resulting in inequalities for understanding difference (McCall, 2005). On the other end of the spectrum is an approach called intercategorical complexity, where researchers use existing categories to explore inequalities along different dimensions (McCall, 2005). In the middle lies intracategorical complexity, or a "group centred" approach (Choo & Ferree, 2010), where the intersections of multiple aspects of identity (such as race, gender, and sexuality) become a focus for discussing the experiences of a single group, like "Black lesbians" (e.g., Moore, 2012). This approach questions the process that created the categories, thus taking a critical stance toward them, but recognizes that these social categories symbolize firm relationships (McCall, 2005). My approach to this project fell somewhere within inter- and intracategorical complexity. I used the existing categories to which the women reported they belonged and perceived as relevant to their own view as a means exploring inequalities along these different dimensions. However, while there were some similarities in the women I interviewed, they could not really be presented as a "single group," and I did not even feel comfortable with this type of essentializing of my participants. As such, I cannot consider this analysis fully intracategorical in nature.

Having described the philosophical underpinnings of this project as they relate to my methodological approach (i.e., qualitative, feminist, and intersectional), I move now



to presenting a reflexive account of my role in this research and discussing the challenges I faced while undertaking this project.

# **Researcher's Role and Challenges Faced**

Before I report on the methods I actually employed, I would like to situate myself within the research and address the challenges of this project. I do this at the outset for several reasons. First, this type of reflexivity is aligned with my epistemological position. Second, my topic is one in which I have extensive personal experience. I myself attended a women's health centre with the understanding that the services were women centred. I was also not satisfied with these services, and did not agree with the physician primarily responsible for the centre that the services offered were women centred. I identified with the experiences of my participants, and felt that I could relate to their frustrations and criticisms. As such, I have to acknowledge this particular bias before I present the results of my analysis. While my own personal investment may be seen as a limitation, I believe it can also be seen as a strength. The language my participants used was familiar, and I felt that we connected during the data collection process even if I never met a participant face-to-face.

Beyond this personal investment, this research was very difficult to undertake and involved several challenges that I felt I needed to address in the methodology chapter. I spent almost six months trying to secure organizations to participate, then a full year attempting to get ethics approval from the various organizations who finally agreed to participate. When these attempts failed to bring me any participants, I spent another several months recruiting participants through a means that can only be described as "Plan D" (i.e., it was the back-up to the back-up to the back-up). I speak frankly about



these difficulties because it highlights a particular challenge for all researchers attempting to document patient experiences in our health care system; these participants are really difficult to access. While it is possible that this particular line of research was potentially too difficult at the dissertation level (i.e., I am still only a student, lacking funding or a true title to give me "credibility"), I also believe that we will have to be more creative in the future to truly hear patients' voices. There may well be a reason for the lack of patient experiences in the literature beyond a simple preoccupation with providers' opinions; it is hard to recruit patients.

A fourth and final reason for this declaration and the extensive "challenges" section appearing in my methodology section is that my data collection techniques changed greatly from what I first proposed. I had been warned by my wise committee members that this would be a challenging process, and I should have heeded their advice. From the proposal to the final product, things did not always go as planned. While this is likely a common experience for many researchers at any level of their careers and for a multitude of projects, it was my first experience with the process going very poorly. These are lessons I will carry with me for the rest of my academic career.

In the remainder of the chapter I have attempted to present my participants and methods with clarity and transparency. However, I would like to first contextualize my actual data collection methods by describing my first few attempts at collecting data. Initially, I identified 30 women's health centres in the summer of 2009 as potential data collection sites. Immediately, almost half were removed due to phone numbers that had been disconnected, emails that no one answered, or websites that did not work. By January, several of the facilities had closed due to lack of funding, mandated



restructuring, and amalgamations. For example, in two central Ontario cities (at least), the community locations closed and the hospital location became the only women's health centre available. My initial hope had been to identify a community-based centre to partner with and collect data from in person. I believed that such a facility would be more likely to adhere to the Hills and Mullet's (2002; 2005) prescribed principles for women centred care, that it would be easier to apply the intracategorical form of intersectional analysis due to all the women coming from the same place, and that it would be easier to achieve ethics approval from this type of facility as opposed to a hospital. With many of the community locations closing, it was difficult to meet my goal.

At the first phase of my data collection, I attempted to recruit directors of women's health facilities to complete a phone interview or an online survey. I ended up with a final sample size of four, which is clearly smaller than I had hoped. Some of the difficulty came in trying to get past the administrative assistants at the facilities. These individuals took messages for the directors, or told me that someone would call me back. In most instances, I was never directed to a private line, but rather to the assistant as gatekeeper to the person with whom I actually wanted to speak. Of the three individuals who initially completed surveys, two directors agreed to be contacted for further components of the research, though neither returned my calls and emails as I later attempted to find a partner for my interviews in phase two. A second search for additional women's health facilities, and a "double-check" to ensure I had exhausted my initial list, was fruitful. I got in touch with a fourth director who was very interested in my project. She ended up being the final participant in phase one of my research.



Following this first phase, I had hoped to partner with one of the organizations that had participated in my data collection in order to conduct phase two, but was never able to reconnect with the first three participants. Following the second search for women's health centres, I identified additional facilities that did not participate in my first phase of data collection. I contacted several with the hope of interviewing patients, but was told each time that they did not allow research to be conducted with their patients. For these facilities, it was a means of respecting their patients' rights and privacy. Two centres did not even allow their own staff to collect data for research purposes. I realized that I was fighting a losing battle in trying to secure a community-based health centre, and decided that a hospital would be an acceptable back-up location to recruit from. The process of finding facilities from which to recruit participants was useful in that it revealed to me an important preconception I held. That is, I was making assumptions about what types of services were offered, and which types of facilities would render the "best" kind of data.

As I mentioned, I was able to connect with a fourth and final director after this second search. I remembered that I had initially targeted London as a prime location because it was within driving distance. At my initial recruitment for phase one, I had been told that the community centre, Women's Health of London, was closing its doors due to lack of funding. There had also been an administrator for the Women's Health Care Centre at the Victoria Hospital who was interested in my research, but did not know who should complete the survey. The two London hospitals (i.e., Victoria and St. Joseph's) had been in the midst of restructuring and were attempting to place one person in charge of the women's services in both locations. After a second email had gone



unanswered I had moved on, but believed enough time had passed that I could try again, and hoped to be put in contact with the new director.

This time around, I got in touch with the new Director of Women and Children's Ambulatory Care, who was very interested in my project. She agreed that I could recruit from both the Victoria and St. Joseph's locations. I attempted to obtain ethics approval for this new development. In order to collect data, I needed to gain clearance from three locations: the University of Windsor, the University of Western Ontario, and the Lawson Health Research Institute (LHRI) through the London Health Sciences Centre. These last two locations were required by the hospitals. Unfortunately, I was met with a cyclical challenge; no one would grant me approval until the others had first granted me approval. Eventually, the University of Windsor granted me a provision that they would approve the study if I managed to secure the appropriate signatures from the other two locations. After almost one year and several changes made by the LHRI (including where I could post my recruitment flyers and the size of the recruitment flyers), I was finally granted approval in December 2010, more than one year after I had proposed my project.

The hospitals allowed me to post flyers to recruit with the following restrictions: the flyers must be no larger than 8.5 by 11 inches (i.e., standard paper), could not contain the message that participants would be compensated for their time, and could only be posted in three physical locations within the hospitals. See Appendix A for a copy of this flyer. I was directed to these locations and became immediately concerned. There were already dozens of recruitment flyers, many of which did contain information about compensation. I dutifully posted my flyers, and waited for a month before taking further action. When I returned to the locations later, some posters had been moved or fully



removed to make place for new ones. This presented a new challenge; I was now almost a year and a half removed from my proposal with nothing more than four online surveys completed. I decided to try one more method of recruiting data; I went to the women's health centre that I attended in Windsor.

For me, this development was not optimal. I was not satisfied with the care from my own health centre; I did not believe that this was a women centred facility, even though the physician in charge claimed that it was. However, I believed it possible that my own preconceptions about what women centred care is had been shaped by my reading, and that one of the questions I was trying to identify was whether that model worked in Ontario. As such, it was possible that other women would see this facility as women centred even if I did not. I contacted the doctor and she was very open to the idea. She let me post flyers in her waiting room and the patient rooms with the hope that she would also gain some valuable information from the responses. I used the same flyers as I did for the hospitals, but replaced the compensation information.

Ultimately, I had learned my lesson in waiting a year and a half to actually recruit participants; I needed a back-up plan. Beyond this new approach to collecting data, I also decided to recruit online. When I was not able to recruit even one participant from the flyers placed in the Women's Health Centre in Windsor, it was my preparation for online recruitment that actually allowed me to collect data. Having addressed these challenges as a means of contextualizing why I collected my eventual data the way I did, I will now simply address the methods I employed to undertake two phases in this project. In the first phase, I explored how women's health centres operated in Ontario (i.e., whether they



adhered to Hills and Mullett's (2002; 2005) principles of women centred care). In the second, I explored women's experiences with Ontario women's health centres.

# Phase One: Profiles of Women's Health Centres

Participants. Participants included four directors or coordinators of women's health facilities in Ontario. Three of these facilities were hospital based, and one was community based. Women's health centres were identified in various cities across Ontario through online searches of women's health listservs and databases (e.g., Ontario Women's Health Network or OWHN, and Canadian Women's Health Network or CWHN), search engines (e.g., Google), scholarly databases (e.g., PsycINFO and CINAHL), word of mouth, and directly contacting women's health organizations (e.g., OWHN and CWHN) and other lead organizations (e.g., Local Health Integration Network or LHIN). In total, 17 health facilities were contacted (see Appendix B for a list of health facilities). Six directors started the survey, but only four completed it. The two directors who did not complete the survey only initiated the survey by entering their emails and then did not complete a single question. Participants were contacted through telephone and email, given background information about what this project entailed and the practical importance of the potential findings, and asked to complete a brief online survey regarding their centre's services. Participation was voluntary, and confidentiality assured if it was desired. In all but one case, the director agreed to have the name of the facility associated with my analysis.

**Methods.** Following a telephone or email contact, participants were sent a letter of information and link for the online survey, which also provided instructions to print out the online consent form for their records in accordance with my approval from the



Research Ethics Board (REB). The survey, administered online via Perseus software, was a combination of open-ended and closed questions regarding the principles of women centred care employed by each centre. The directors were linked to the online consent form, which required them to click "I Agree" (to participate) or "No Thank You" (if they chose not to participate). After two weeks, if the director had not responded, a friendly follow up reminder was sent (Dillman, 2007) via Perseus. My ability as the primary researcher to track their participation based on email addresses, and thus identify each centre's responses via email, was made clear in the consent form. Please refer to Appendix C for a copy of the consent form and Appendix D for a copy of the survey.

**Data analysis and considerations.** This survey was developed specifically for this study, and was largely exploratory in nature, meaning that if I had erred in including an issue that was not relevant to Ontario health facilities, there was ample opportunity for the directors to identify this issue as problematic. For example, one facility noted that they did not in fact consider themselves women centred.

The goal of phase one was to classify Ontario women's health facilities as women centred according to whether they followed Hills and Mullett's (2002; 2005) principles of women centred care. As such, a qualitative profile was created for each centre. This profile included the name (if the centre agreed for it to be shared), location (i.e., city or general area of Ontario), population of women served, vision or mission statement, aspects of Hills and Mullett's model adhered to, and other relevant information. Following the creation of each profile, I had intended to conduct a classical content analysis to categorize centres according to the aspects of care they adhered to. A classical content analysis involves systematically and quantitatively describing the data into



themes that can be counted with regard to how often they occur (Leech & Onwuegbuzie, 2008). Unfortunately, too few directors participated and the sample was too homogeneous to make this exercise practically useful.

There was wide variance in the descriptions of each centre's mandate, but there was almost unanimity in the principles each centre purported to adhere to. Because of the homogeneity in my data, and lack of practicality in a separate classical content analysis, I decided to address the findings of this phase in two important ways. First, I provided profiles for each centre as Appendices E through H. Second, I addressed what this phase contributed to my subsequent data collection, and provided some critical discussion of these findings as preliminary, exploratory issues in the first of my results/discussion chapters.

Very briefly, because most of this discussion will come in the results chapter, this survey provided me with some important information for the second phase of my data collection. Namely, I was alerted to terminology being used by Ontario women's health centres that I had not considered before: family centred care. The benefits were two-fold. First, I was able to improve my interview guide for phase two by using language that was relevant to the Ontario health care setting. Second, I improved the literature review and analysis for the entire study based on a clearer understanding of the state of health care services directed at women in Ontario.

# **Phase Two: Women's Stories**

**Participants.** Participants included seven women who had attended or were currently attending a women's health centre in Ontario. Further details about their identities are presented in the next chapter. These women were recruited online from



women's health websites and message boards (e.g., CWHN, Health Boards, Women's Health Matters, Women's-Health), newsletters (e.g., Brigit's Notes: A women's health ebulletin), listservs (e.g., OWHN listserv), and Facebook (e.g., CWHN Facebook page). I placed a brief message looking for women to participate in an hour long interview, either over the phone or in a place I could travel to at their convenience, noting that they would be paid \$20 for their time (see Appendix I for this recruitment notice). The women could call me or email me to set up an interview time. Following the initial contact, I emailed the women a copy of the letter of information and consent (see Appendix J). Although I could not procure a signed copy of the consent form from the women, prior to the commencement of the interview I read the form with them and the women gave me verbal consent over the phone, in line with the requirements of my REB approval.

Recruiting women was, admittedly, a daunting challenge as I have detailed earlier in this chapter. At least four more women contacted me to set an interview up, but either ignored my follow up emails, or could not set up a workable time. However, a sample size of seven is normative for IPA (see Brocki & Wearden, 2006; Smith & Osborn, 2007; Turpin et al., 1997). There was no "necessary" or "correct" number of participants because the emphasis here was being placed on a detailed exploration and analysis of each case.

**Methods.** Each woman was interviewed once in a long interview format (McCracken, 1988) conducted over the phone at a time convenient for them. Although there was a potential disadvantage of not being able to establish rapport as easily with the lack of face-to-face contact, this did not prove to be much of a concern. The women responded to my questions in a satisfactory way that allowed me to conduct a meaningful



analysis. The long interview format allowed for an in-depth exploration of participants' experiences, and required me to undertake a review of my own values and biases (McCracken, 1988). This step was particularly important for conducting research that was intersectional in nature, but also because I attended a women's health centre myself and did have experience with this paradigm of health care.

Interviews ranged from 45 minutes at the shortest to two hours at the longest, and were used to seek narrative (i.e., storied) data. Although I had advertised the study as only taking an hour, I allowed women to speak at their leisure; no participant mentioned how long the interview took. An interview agenda, rather than an interview guide, was used to allow for probing and inductive exploration of participants' lived experiences while also allowing for flexibility. After introductions, I said, "Tell me a little about yourself," and once they had described themselves I asked, "Tell me about the women's health centre you are attending/did attend" if they had not already started to discuss their experiences there. At that point, I used a basic agenda with probing questions to keep some direction and flow to the interviews, but largely allowed the women to discuss things they felt were important. It is worth noting that many of these women had health conditions that they only discussed once they were partway through the interview. In my initial agenda (see Appendix K), a request for the women to talk about their health needs was placed very early in the order of questions. If I had gone with a guide instead, it is possible the women would not have been so honest and forthright with their answers.

At the conclusion of the interview, I asked the women if they were interested in further resources related to women's health. If so, I sent links to women's health websites (e.g., OWHN, CWHN) and forums (e.g., Women's Health Matters) via email. I also



asked how the women would like to receive their \$20 for participation. All seven women asked me to mail a check to a preferred address.

I conducted the phone interviews using Skype in order to use the recording software Total Recorder. This software allowed recordings to be saved as .wav files on the one password protected computer being used to store data, and allowed for easy play in Windows Media Player when I undertook transcription. Interviews were transcribed verbatim (five by me, and two by a paid transcriptionist) and sent to the participants for authentication (See Appendix L for a copy of the Transcriptionist Confidentiality Agreement). Only two women responded back saying that they were fine with the transcriptions, and in one case a woman clarified three sections that had been unintelligible based on the quality of the recording. While I had intended to give my participants a chance to member check and authenticate their individual narratives postanalysis, I did not move forward with this option based on the poor response at the first round of authentication. Although this authentication step was not promised to my participants, I will still address this potential limitation in my final chapter.

**Data analysis.** The data were analyzed using Interpretive Phenomenological Analysis (IPA; Smith, 1996). My analysis largely followed the step-wise process of IPA outlined by Smith and Osborn (2003). My reasons for selecting IPA, and in particular Smith and Osborn's method, were two-fold. First, I was seeking to extract narratives that would allow my results to represent the stories these women told about themselves (Crossley, 2000). I have already detailed how narratives are useful in terms of applying an intersectional analysis, but IPA is also a particular form of analysis that is concerned with translating qualitative data, and the themes found in qualitative analysis, into a



narrative account (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2003). Second, I was looking for a way to be systematic in my analysis, especially because I had such long transcripts from some of my participants, and needed a method that would keep me organized. Smith and Osborn's method provided five general steps that were well described and could be conducted using any word processing software.

Before I detail the five steps of my analysis, it is important to note some shortcomings of IPA. In particular IPA can be problematic both when researchers believe that what they have been told by their participants is "empirical truth," and when researchers fail to acknowledge that the participants' words have been constructed in a particular way for a research interview (McAdams, 1993; Parker, 2005). In other words, it is a contrived setting, serving a particular allegorical purpose, using certain types of cultural capital, for the benefit of a specific audience (Parker, 2005). Researchers may also have a tendency to make inaccurate inferences about the intentions underneath a person's words; to "discover" underlying mental processes that may not be present; or to focus on an "inside" perspective that may not exist, and is in fact dependent on the research context (i.e., the contrived setting being ignored; Parker, 2005). Having acknowledged these shortcomings and those of the sometimes problematic notion of "giving voice," and having attempted to be cognizant of them throughout my analysis, I felt that I could move forward with an IPA as a means of giving my participants agency and providing a meaningful analysis of their narratives.

In step one my analysis began with several close readings of my first transcript. Notably, I analyzed the transcripts in order of when I conducted the interviews, and for no other reason or rationale. I highlighted sections of the text and made notes to myself



on the right margin using the Track Changes function in Word. These notes included summarizing and paraphrasing, interpretations, and a preliminary attempt to connect different sections of the transcript. For example, responses that dealt with the women's "identities" could be found throughout the transcript, rather than in just one section.

Once I had annotated the entire transcript, I moved to step two: identifying emerging themes from my notes. While Smith and Osborn (2003) suggest using the other margin, I simply created another Word document to keep open at the same time due to limitations in using Word. Initially there were a multitude of themes based on my very broad notes to myself. After the entire transcript had been explored for themes, I was able to complete step three, where I looked for connections in the themes I had identified in order to create superordinate themes in that transcript. Once I had identified these superordinate themes, I went back to the data to make sure that the participant's words reflected these sub-themes. This meant I produced a table for that participant, listing the superordinate themes and places in the text where these themes occurred.

In step four, this entire process was repeated for each participant (see Appendices M through S for these analysis tables). Smith and Osborn (2003) note that it is possible to either use the themes from the first transcript to orient the rest of the analysis, or to create a whole new set of themes for the other transcripts. I felt that it was too difficult to simply "put aside" the analysis I had already conducted, and that it would be a falsity to say I had not considered these themes in my subsequent analysis. As a result, I did use the previously found themes as I analyzed the other transcripts, but was diligent in allowing other, new themes to emerge. In many instances, a new theme would emerge in a subsequent transcript that forced me to go back to previous transcripts for another look.



Once all seven transcripts had been analyzed in this manner I completed step five, where I explored the themes across the participants and created a master table (see Appendix T). In some instances, this meant collapsing several themes into one larger category. In other instances, I kept the themes separate.

Having "completed" the five steps of the IPA, I felt that the analysis was simply not enough to truly give a sense of who my participants were; the women's individual histories and identities were crucial to their experiences with the health care system. In order to "do justice" to their stories, I went back to each transcript. Using the analysis for each individual transcript, I created a personal vignette for each woman. I hoped that these brief narratives would provide some context for a potential reader of my research. Once I had completed these vignettes, I saw several "holes" in my understanding of who these women were. For example, I had not specifically asked about the educational history of several of the women, and would be forced to postulate this demographic characteristic based on how articulate and informed their responses to my questions had been, and on their other personal experiences. Although it may be perceived as a limitation not to have asked very specific and pointed questions about the women's demographic characteristics in order to gather the same information from each participant, I was trying to allow the women to provide me with the experiences that mattered most to them. Nonetheless, I realized I could not include some aspects of their identities in my intersectional considerations based on simple "postulations." I went back to the IPA and tried to apply the intersectional analysis in a much more conscientious way; I did not want to make any conclusions that went beyond what my research could actually say. I also see this as an example of how I attempted to continually address the problems with



"giving voice." That is, I allowed the women themselves to drive the descriptions of their identities I arrived at, rather than me choosing for them. I believe that the final analysis is stronger for this extra step, but I should also acknowledge that the analysis is still purely my own. No one else reviewed my categories, and time did not allow member-checking by my participants.

**Evaluative criteria and ethical considerations.** "Narrative analysis" as a general category of analysis for storied, textual (i.e., talk or document) data acknowledges the potential of stories to give meaning to individuals' lives (Leech & Onwuegbuzie, 2008). Based on my creation of vignettes for each woman, and the larger IPA to explore themes across their experiences, two types of reasoning were used; narrative reasoning (i.e., narrative analysis; Polkinghorne, 1995) was employed to generate a story for each woman, and paradigmatic reasoning (i.e., analysis of narratives; Polkinghorne, 1995) was used to classify and categorize in the IPA (Bruner, 1986). Some of this work required me to "reduce" data to a summary of the main "plot" of participants' experiences (Leech & Onwuegbuzie, 2008). Keeping this process in mind, especially because I alone applied this analysis and it is my personal interpretation of the data, it is essential to address how I ensured the quality of my work.

Qualitative research clearly involves its own evaluative criteria. Researchers have identified specific criteria that can be applied to forms of narrative analysis. For example, "trustworthiness" can be appraised with regard to the descriptive, interpretive, and theoretical components of the research. I believe I have met this requirement by staying immersed in the literature, most notably by informing myself of Ontario-specific issues (i.e., conducting phase one), and continuing to improve my knowledge of the specific



context within which I collected my data. Additionally, credibility, or the accuracy of the data (Polkinghorne, 1995), believability, or that the portrayed results convey the events and encounters as they were actually experienced by the participants (Blumenfeld-Jones, 1995), and fidelity, which binds 'truth' with the researcher's interpretation (Blumenfeld-Jones, 1995), have also been identified as areas of concern for narrative inquiry. While some of these concerns could have been addressed if participants had authenticated the analysis, I did not complete this stage of the research. I also largely see these concerns as tied to the problematic use of IPA (e.g., seeking empirical truths, etc.) and using this form of analysis to make conclusions that go beyond the data, which I elucidated above. However, as I have noted, the lack of authentication does mean that the participants did not have a chance to confirm that these stories represent events as they experienced them.

Ultimately, I held reflexivity as the primary means of ensuring the quality of my work, and used Parker's (2005) guidelines for quality research to answer the following questions. First, was my work grounded in previous research? Again, I believe I did ground my line of inquiry and analysis in previous research, and that this was both contextualized and informed by my methods (i.e., conducting the first survey with directors of women's health centres). Second, was there some coherence to my rationale and argument? I believe there was a linear, narrative process that allowed me to make my final conclusions, and that this process was made possible by my thorough use of IPA and intersectional analysis. Third, was my final account accessible to others? At this point, I have not fully addressed this component of quality research, but intend to disseminate my results to both the academic and non-academic communities to make my findings "matter."



Lastly, I would like to address some of the ethical considerations of this research. In the next several chapters, which present the results of my analysis, I have attempted to protect the identities of my participants with the use of pseudonyms, and by removing any further potential identifiers, such as the cities they lived in, and names of the facilities they had accessed. While most of the women can be seen as high functioning, several of them were suffering from serious health issues. For any of these women to have found my recruitment notice, they must have been online, and already connected to some type of women's health community (e.g., forum, website, listserv, etc.). In other words, they were women who were interested in and concerned with health care issues. The women did not mention any negative consequences as a result of having participated in my research, such as emotional pain associated with recounting their experiences with a health issue. I attempted to address any concern of leaving the women without supports following this research by sending them additional information and resources on women's health, and by mailing the women thank you cards for their participation with my contact information, along with their \$20. This gesture seemed to make two women in particular feel supported and valued.



# CHAPTER III

# **Results and Discussion: Phase One and Preamble to Phase Two**

The purpose of this chapter is two-fold. First, I would like to present the findings of phase one. Second, I would like to set the stage for the remaining results/discussion chapters, which are all based on the analysis of phase two.

# Phase One: Profiles of Women's Health Centres

In phase one, I asked directors to identify Hills and Mullett's (2002; 2005)

principles of women centred care to which their facilities adhered. Of the participants,

three represented hospitals and one represented a community-based centre. See Table 1.

Facility Type	Location	Self-Identify as Women Centred	Principles of Women Centred Care Adhered To	Other Principles Identified
Hospital	Central Ontario	Yes	All but: 11 – Other factors 15 – Cooperation of mutually supportive health professionals	N/A
Hospital	London	Yes	All but: 11 – Other factors	N/A
Hospital	Owen Sound	No	All but: 11 – Other factors 12 – Recognize gender imbalances 19 – Gender sensitive	N/A
Community	Toronto	Yes	All	Recognizes racism, other oppressions

Table 1Summary of women's health centres



Of the 19 principles I asked the directors about, only four principles were not unanimously selected by the facilities as being important to their services. The first, allows for cooperation with mutually supportive health professionals, was only not selected by one hospital facility. The second and third, recognizes gender imbalances and is gender sensitive, were only not selected by one (different) hospital facility that did not identify itself as women centred. The fourth, *other*, was not selected by any of the hospital locations. In this case, only the community-based facility selected *other*, and provided the example of "recognizes racism and other oppressions (e.g., sexual orientation)." Notably, every single principle was selected at least once. This seemed to suggest that directors of Ontario women's health facilities, whether hospital or community-based, largely believed that they were adhering to Hills and Mullett's (2002; 2005) principles of women centred care. Once again, however, only three of four centres actually identified themselves as women centred. The fourth, a hospital, identified as family centred, but still largely adhered to Hills and Mullett's principles. As aforementioned, see Appendices E to H for detailed profiles of each centre.

At the proposal stage, I had been solely interested in understandings of the term "women centred" as a paradigm of primary care offered at women's health centres. Following the online surveys I conducted with directors of women's health facilities, I realized that the term "family centred" was also potentially being used in Ontario women's health centres. Minimally, the terminology was being used in some women's health units at hospitals. As such, I thought that the women I interviewed in phase two might have more familiarity with this language and approach to health care. As I noted in



the methodology section, this was one major contribution of phase one to my overall project.

The responses of the director of the family centred facility, in particular, significantly shaped my analysis and interpretation of the women's experiences in phase two. This director noted that they did not consider themselves women centred, saying:

Women centred is not a term we use - we typically use family centred. Women centred would mean ensuring care and treatments are appropriate for women, that research and trials included women to establish findings, that the whole woman is considered in treatment and plan of care - emotionally, socially and physically. Based on this response, it was not clear if this particular facility still adhered to the

director's definition of women centred care and just called it family centred, or if they did not include a women centred approach at all. Later in the survey, the director was asked what other types of approaches their facility adhered to. Interestingly, she responded, "Family centred - there is movement within the hospital to move to a patient centred approach. Family centred care is the norm for us - women centred is essentially synonymous."

I was perplexed that the terms were basically seen as synonymous; in the same sentence, she used women centred, family centred, and patient centred to largely refer to the same approach to care after specifically saying that they were not women centred. If the facilities themselves could not differentiate these terms in a meaningful way, I wondered how the women who accessed services there would experience them, and if these distinctions were even relevant, practically speaking. As a result, I also asked the



women in phase two about their understandings of women centred, family centred, and patient centred as different approaches to care.

Because my final sample was so small and homogeneous, it is difficult to generalize to other Ontario women's health centres. These four facilities represent only three of 14 Local Health Integration Networks (LHINs; South West, Central East, and Toronto Central). Management decisions vary by LHIN, making it difficult to say that these findings are anything but preliminary and exploratory. However, this phase of my research was important for several reasons. First, as I have already mentioned, I changed the interview guide to accommodate for Ontario-relevant language (i.e., family centred care). Second, this phase revealed to me that directors or coordinators of women's health centres in Ontario largely did, in fact, perceive that their facilities adhered to Hills and Mullett's principles of women centred care, if those principles were presented as choices from which to select. Ideally, I would have asked the directors to elaborate on their own principles themselves. While I employed small q methods here to explore this issue, I believe a more useful exercise would have involved using Big Q methods to allow the directors to identify and elaborate on these issues themselves. Unfortunately, it was difficult to recruit these participants even with a convenient online survey. I believe it would have been an even greater challenge to recruit participants for interviews.

The third contribution of this phase to my overall project was that it validated the inclusion of Hills and Mullett's (2002; 2005) model as a framework for my research on women's health centres because the principles were almost unanimously selected (even when centres did not define themselves as women centred). Preliminarily, this might suggest that Hills and Mullett's principles are relevant to and employed by women's



health centres in Ontario, even if these facilities do not explicitly label themselves as "women centred." Future research will need to examine how these principles are adopted by other women's health centres across Ontario; we need to clarify if there is a difference in care depending on whether the facility is a hospital or community-based centre, and we need to explore whether or not classifying themselves as women centred is meaningful. Similarly, we should address the issue of whether or not any of these distinctions between health care paradigms (e.g., patient centred, family centred, and women centred) are of any use, practically speaking. Unfortunately, at this point I cannot make any real conclusions about facilities classifying themselves as women centred, nor about the meaning derived from this classification. This exploratory study has revealed future directions, however, and as such is a useful contribution to the area.

Now that I have presented the results of phase one, and how they contributed to my overall project, I will introduce my results and discussion for phase two.

### **Phase Two: Women's Stories**

I would like to present a brief vignette for each of my participants and myself before I describe the results of the Interpretive Phenomenological Analysis (IPA). I offer these narratives to contextualize the women's experiences and bring greater understanding to their choices and concerns that I will discuss later in the results of the IPA. I would also like to reflexively situate myself in the actual analysis.

Undertaking an intersectional analysis meant exploring the various ways that aspects of the women's identities intersected to inform who they are. At first glance, the women appeared to have some similarities; most identified as heterosexual or were in a heterosexual relationship, were of the middle class, and had some formal education.



These elements of privilege needed to be considered as I analyzed the data and tried to understand how the women had experienced their health care. On the other hand, the women's histories differed in important ways; several had experienced poverty at some point in their lives, most of the women had different but significant health concerns, and their ages varied. These factors that both connected the women and distinguished them from one another contributed to the women's unique understandings of their health needs, and their experiences in the Ontario health care system.

It is worth noting that the women had different levels of experience and types of engagement with a women's health centre. For example, some of the women had attended a women's health centre in the recent past but were not currently seeking services there, while others were currently using a women's health centre (or two). The difference between these two groups could be explained by several factors, which I will address in the IPA. A few of the women had received most of their health services, including annual physicals, from their women's health centre. Several attended on a needs-only basis, or for community programs. These differences also contributed to their unique perspectives on women's health services.

Another factor that must be addressed is the locations of my participants. In the following vignettes, I have chosen not to identify the women's locations in order to protect their identities. These women came from several places across Ontario, representing five LHINs: Erie St. Clair, Hamilton Niagara Haldimand Brant (HNHB), South West, Toronto Central, and Central East. Because each LHIN varies in how it addresses its unique issues related to health care access and budget constraints, these women's experiences with their health services must be contextualized within their



locations. However, all Ontario LHINs are currently facing a deficit of family medicine practitioners (Singh, Lalani, Kralj, Newman, Goodyear, Hellyer, et al., 2010). As of 2008, estimates for my participants' locations placed these shortages at approximately 51 physicians for Erie St. Clair, 46 for HNHB, 69 for South West, 97 for Toronto Central, and 93 for Central East (Singh et al., 2010). Because the shortage is so pervasive, I felt that these women's experiences were meaningful for similar Ontario women.

To give you a sense of how I arrived at my final analysis, here are (my versions of) the stories of "Jane," "Patty," "Julie," "Sarah," "Laura," "Cheryl," and "Helen." My perceptions and understandings of their accounts were certainly shaped by my own experiences, values, and biases. As a result, the last vignette I present is my own.

# Vignettes

**Participant 1: Jane.** Jane was in her 60s, retired, Caucasian, and living in rural Ontario. Money was a concern for her; she found it difficult to live off her and her husband's combined pensions. Although she did not consider herself impoverished, she was living in the lower-middle class. She did not declare herself heterosexual, but was in a heterosexual relationship, and in her early sixties. Her level of education was not clear (this was one of the few interviews that I did not ask explicitly), but she was very articulate and informed on policies and news related to women's health. She had also had the chance to travel and live abroad, and had thus been exposed to several different perspectives of health care and health care policy. Jane said she had reached menopause and that she had also suffered from depression periodically during her life. She had dieted off and on as an adult and had concerns about this aspect of her health as well. She believed that her concerns and focus on her health had grown as she aged, and seemed



concerned about the health of all women who lived in her area. In particular, services had recently been cut and the cost to get to the current women's health centre was increasing.

Jane was someone who wanted to have a say in how her health care was provided to her. She was angry that services had been cut, and that there had been no consultation with patients in how the restructuring of services had occurred. She had originally arrived at the community-based women's health centre in her city through a friend and newsletter distributed by the facility. There had also been a hospital-based women's centre available, but Jane preferred the community-based facility. Although she did not have access to a doctor there, she had a nurse practitioner who was very informed about alternative treatments and research related to several women's health issues, and in particular menopause and depression. Jane regularly accessed the library at the women's health centre, and had appreciated the range of educational and support programs available.

When the downtown community-based facility closed, all services, including the nurse practitioner, were moved to the hospital facility. The hospital was less accessible in terms of public transportation, and also cost more to park if you drove your own vehicle. Although the library was still available at this location, it was difficult to find because it was housed in a larger building. In the past such services had been advertised through the facility's newsletter, but with cuts this advertising disappeared. Many of the programs were also cut, to the point that Jane believed that only an anorexia group and breastfeeding group remained. (Note: On further inspection this was not correct. For example, a menopause support group remained. However, Jane was correct that few of the original programs continued to exist).



Jane felt that her voice had been minimized and that she had no say in how her health care was being offered to her. She felt like a "trouble maker" because she wanted to have a voice. She had truly loved the downtown facility, but now felt overwhelmed by the hospital program and angry that many of the things she had appreciated were gone. She felt that patients did not come first, and instead that money was the major concern for health care providers. For Jane, women centred care was largely a "politically correct" term that was being offered "in theory" rather than in practice. However, she believed there was an important difference between "true" women centred care and family centred care. Women centred care meant that women could be respected, heard, and part of the decision-making, while family centred care meant taking care of families' needs. Jane noted that not all women were part of traditional families with children and believed that family centred care would not meet all women's needs. She believed that women centred care was not just about physical health, but that other types of health (e.g., mental) mattered too.

**Participant 2: Patty.** Patty was a 50 year old woman. Although she did not mention a partner of any kind, she did say that she was a single parent until her daughter died. She did not mention whether she had received formal education, but was very articulate. She also talked about having to educate herself in terms of medical language in order to have meaningful conversations with her daughter's doctors. (Note: This would imply at least a high school level education, but this is only speculation.) Patty mentioned several interactions with the health care system that would suggest she had had several health issues and had been marginalized by the system. First, her daughter died of leukemia in her early teens, meaning that Patty had spent a lot of time in hospitals.



Second, Patty had entered menopause and often spoke of its negative effects. She also experienced a great deal of pain during her pap smears, was a stroke survivor, and suffered from post-traumatic stress following the death of her child.

Patty did not mention any personal financial difficulties, and did not divulge her career. She did mention that she lived closer to the hospital than downtown and lived in an urban environment rather than rural one. She was concerned with the cuts being made to health services, and was very clear that she saw herself in a "battle" with the health care system. Her concerns with health and health care had increased with age, but she had a lot of experience in dealing with medical personnel from the time that she was very young. In Patty's estimation, many doctors lacked the ability to connect with patients on a "human" level, and she had experienced this first-hand on several occasions. She often felt like a number as opposed to a person, and believed that in order to get anything she needed from the health care system, she literally had to fight. Without patient advocacy, she believed very little could be accomplished.

Patty had initially come to the women's health centre through committee work. She had been working on a committee for the hospital, and a member of the women's health centre was also on that committee. This person described the range of services, including physicals, and Patty decided that with her history of suffering from painful physicals at the hands of regular general practitioners, she needed to check the services out. Two options had been available: a community centre downtown, and a unit at the hospital. She started at the downtown facility and really appreciated the services there, even though it was further from where she lived. Once the downtown facility closed and the hospital was her only option, she attempted to move to that location. Unfortunately,



she was forced to get a referral to a facility she was technically already attending. When that did not materialize for over a year, she simply went without primary care.

Patty did not put much stock in the notion of women centred care. She did believe that women had different health needs from men, but that these were largely physical in nature. The whole reason she attended the women's facility in the first place was because she thought they could give her a painless physical, and they did. She thought the women's health centre was particularly useful for younger women who needed pregnancy or abortion assistance. In the health care setting, Patty placed more importance on a sense of community among patients and families suffering from the same issues, of having patients treated like people, and putting patients first.

**Participant 3: Julie.** Julie was a 28 year old woman with children. She was living in an urban space, but did not have a doctor in the area. As a result, she drove six hours twice a year, or whenever her children needed an appointment, to see her general practitioner. Julie did not identify whether she had a partner (male or female), nor did she identify her line of work. However, she was a co-founder of a women's advocacy group, and had found out about my research while looking for women's health resources online. She belonged to a women's health listserv, and was highly articulate. (Note: Again, this might imply that she had at least finished her high school education.) She mentioned that she liked that Canadian health care was accessible by anyone, and beyond suggesting that more money should be placed towards offering health care, she did not identify a personal financial concern.

Julie was someone with a lot of experience with the health care system. She had recently undergone gastric bypass surgery and now had to receive weekly injections of



essential vitamins. She had also contracted an infection for which she needed to receive fairly regular treatment. Because it was impossible for her to drive six hours every week, she needed a place to receive this treatment and regular physicals; her women's health clinic, with its nurse practitioner, was able to supply some of these services. However, she discussed her frustration with the fact that women over 26 could not get pap tests at the women's health centre, and that she lived more than 30 minutes away from it. The centre was not well advertised, and she questioned how accessible it was to all women in the area, particularly those without a car, as she had been for several years. Even though she was 28, she was highly concerned about her access to health care. She disliked the distance between herself and her general practitioner, and felt grateful for the women's health clinic.

Julie stated she had some understanding of what it meant for a health care centre to be "patient centred" but had never used the term "women centred" and did not feel that her women's clinic was women centred when she thought about what that would actually mean to her. She appreciated the information and services she received there, but felt that women centred care would be "trauma-informed" and that providers in this setting would have the ability to recognize abuse and other mental health issues. She felt that these issues were not being addressed currently. She mentioned that she would love for her children to receive their care at the same facility, but that this was likely a more family centred than women centred model. She was pleased that the women's centre did seem to incorporate physical, emotional, and mental health concerns, and that the nurse practitioner actually treated her like a person. She mentioned that her primary physician had religious values that made her feel judged when she brought up particular concerns.



For Julie, "women's health" was a concern in and of itself that was qualitatively different from simply being patient centred, and she believed that women needed to be listened to in order for their needs to be met. A sense of community, and of women coming together to advocate for their own issues, was critical to her whole approach to her health. The women's health centre she attended, while not necessarily "women centred" as she defined it, had allowed her to receive health care while feeling listened to and not judged.

**Participant 4: Sarah.** Sarah was the youngest of the women interviewed, and in her mid-20s. She had a male partner, and identified herself as Caucasian and cisgendered (i.e., her gender identity matched her biological sex). She had a university education and worked at Planned Parenthood; as a result she was very informed about the health care system and had ready definitions for women centred and family centred care. Sarah was born in the U.S. and had come to Canada midway through her third year at university. As a result of her American citizenship, and changing student/working status, she had gone for periods without OHIP coverage. She used a community health centre and sexual health clinic, which was predominantly a women's health centre but also offered services for gay men, during these times without coverage. However, she continued to use these services even with the coverage and access to her own doctor. Sarah lived in an urban environment and noted that she was privileged in pretty much every way possible, citing ethnicity, age, sexuality, and socioeconomic status as examples of her privilege.

While Sarah was very healthy physically, she did suffer from depression and anxiety. She felt it was incredibly important to have regular access to a health care provider. Again, while she did have a general practitioner, she used the women's health centre and other community centre more often because she preferred the care she



received there. In particular, she related that her female general practitioner had been judgmental about her sexual choices and uninformed about contraception. It was not enough for Sarah's physician to be a woman to make her services women centred; she believed that her physician also needed to be informed about sexual health.

For Sarah, women centred care was pro-choice and required that providers be informed of reproductive rights. She was also concerned for transgendered individuals and questioned whether their rights were met under the title of women centred care. She did not know if the services she had accessed were well known by other women, and believed that part of the problem was that women needed to be savvy online and know where to look for information in order to find such services.

**Participant 5: Laura.** Laura was a 56 year old woman who had originally been born in England but had been living in Canada for about 35 years. She had two children, and was divorced from her husband. Laura had been in the middle class before her divorce, but for much of her life afterward had lived in poverty. When her children were young, she had lived in co-op buildings and only had access to communal washrooms. Laura had a university degree in addition to having received training in childhood education, though the degree associated with this training was never fully discussed. She was also very articulate and informed about her health services. Having been exposed to the English health system, she had actually preferred and desired a midwife for her births but had felt coerced into having a regular doctor in Canada. While she had lived in urban areas, she currently lived in rural Ontario.

Laura had a long history of accessing personal health services for several physical health issues, a learning disability, and mental health issues, and had also been exposed to



different health services for her troubled son. She had also suffered mental, physical, and sexual abuse in her lifetime. She had been through several therapists and general practitioners, and most recently had been without a general practitioner for more than 10 years. She had only had a handful of physical exams in that time. She continued to see multiple mental health providers and access other health related services, but strongly believed that there was little to no continuity of care in the services she had received.

Laura had originally heard about the women's health centre from a nurse practitioner at the sexual assault clinic she was attending. She decided to give it a try and had been "blown away" by the quality and level of services available. Laura had felt respected, empowered, and even physically better just by going to the women's health centre. However, they changed to a different nurse practitioner; she did not connect with this woman very well and as a result, had never returned. In her time at the women's health centre, she had loved their focus on women and the time spent with each individual. For a person in her 50s, and as someone who described herself as marginalized, she had truly appreciated that personalized care.

Laura had many criticisms of the clinics in the area, and felt that she could not possibly return to one unless she was "literally beaten to death." When she attended the women's health centre, however, it had been very different. She felt that the female nurse practitioner there had cared about what she wanted. Laura was very aware that not going for regular physicals, and not trying to find a general practitioner, was likely detrimental to her health. She wanted to do something to help herself, and had just signed up at a YWCA women's support group to explore how she communicated with other people. She was also seeing a therapist, but felt judged by this person and that they were not



really connecting. She was concerned that mental health services were not part of the general provision of health care.

**Participant 6: Cheryl.** Cheryl was a 55 year old woman living in a rural area of Ontario. She had several of her own children, a few other adopted children from her second marriage, and multiple grandchildren. Cheryl had several Bachelor's and Master's degrees, and other diplomas. She had been working in the health sector, but was forced to retire and now ran her own business helping people connect with their spirituality. Cheryl was currently living in an isolated area that was a 45 minute drive outside a major city. She often felt lonely.

Cheryl did not identify with any particular religious denomination, but said she had recently reconnected with her First Nations heritage. She felt that she was currently in the middle class, but in her first marriage, and immediately afterward, she had been very poor. Cheryl was going to be receiving a radical reconstructive hysterectomy in the coming months, and had also suffered many other serious health issues. She had experienced kidney failure and had a blood transfusion, and suffered from depression. She also had asthma and allergies that had dissipated once she moved into the country, and away from a bad marriage.

Cheryl had come to use her women's health centre because of her dissatisfaction with her primary health care provider. She had heard about the women's health centre through her work in health promotion, and attended when she needed an expert on a woman-specific issue. Unfortunately, she had not been fully satisfied with this centre because it could not meet all of her health needs. After considering the distance the centre was from her home, she decided to not go back. In the short time since she had made this



decision, she had found three general practitioners who agreed to take her on as a patient only to disappear from the area before she could even attend an appointment for the first time. During her time at the women's health centre, she had been happy to have female doctors, but felt that only particular health issues (i.e., those related to her reproductive organs) could be dealt with there. She did feel that the women's centre had tried to empower her to take responsibility for her own health, but that this notion had been executed to the extreme. Instead, the providers at her centre took no responsibility for her health, and so Cheryl felt she had to take all the responsibility herself. As such, she did not believe she had ever received women centred care.

Cheryl felt that there was a big distinction between women and family centred care because family centred care would leave out a large portion of women not in a heterosexual marriage with children. It was not that she, herself, felt that a family was only comprised of a heterosexual marriage with children. Rather, she felt that the Ontario and Canadian governments would not recognize any other family unit. She also thought that women and family centred care were different from patient centred care, which she believed was more of a political term used to let doctors avoid full responsibility for their work (i.e., let patients make all the decisions, and not do anything themselves). She believed that a sense of community among patients was one of the most important aspects to health care provision and that in general, current facilities in her area were not good enough.

**Participant 7: Helen.** Helen was a 27 year old social worker who was commuting between two larger cities in southern Ontario. She was engaged to a man, did not have children, and was completing a Master's degree. Helen described how she had



not been concerned with her health until more recently. This recent concern with her health stemmed from deciding to exercise regularly and lose some weight. She had realized how important it was to her to look and feel good. Her most pressing issue was aesthetic in nature and related to the acne she had suffered as a teenager. While previously she had gone for almost four years without a check-up, she had now received two in the last year.

Helen was the only woman interviewed who had actually attended two women's health centres. She attended one because it was a walk-in community health centre and she could not find a general practitioner in the area. Furthermore, she was only living there temporarily while maintaining a home base in the other city, and did not want to put in the effort to find a GP. She had discovered this facility because her fiancé had seen a sign for the centre and knew that it was something she would like. In her home city, she was accessing care from three providers: her general practitioner (a male doctor about to retire), the university health centre, and the women's health centre. For Helen, having a female doctor was of the upmost importance, which is why she had been seeking care beyond her primary general practitioner. She had heard of this second women's health centre through a friend, who was also attending this facility for their options related to dermatological care.

Helen had heard of women centred care, and believed that she was receiving it at both facilities. She believed that a female doctor was most important to this process, because they would understand what she was going through and deal with health issues that were particularly important as a woman. For example, at the women's health centre she had been asked if she had done breast exams, a question that her male general



practitioner had never asked and that she did not know she should be concerned with at such a young age. She believed that women centred care was different from family centred care, but did not believe that any special emphasis should be given to women just because they were women. Her ideal health centre would serve all individuals.

**Researcher: Barat.** I am a 31 year old, heterosexual, cisgendered, Caucasian woman, and almost done with my doctorate. I have been married for five years, and do not consider myself religious. Although I often live paycheque to paycheque, I consider myself to be of the middle class. I am currently living in Ontario, working as a sessional instructor at a university and conducting research. I am very physically active and have always taken preventive measures to ensure I stay healthy (e.g., going for regular physicals, dentist visits, etc.) until this past year. For much of the year, I was living in the U.S. and did not access health care even once, largely for two reasons. First, I was not familiar with the system and did not put in any effort to understand it, and second, I put off dealing with any issues because of my perceived lack of time.

I attended a women's health centre for a couple of years during graduate school. Prior to this time, I accessed health care from the university health centre. I was not dissatisfied with the care given to me by the university practitioners, but wanted to see the same person on a regular basis, and felt it was important to attend a women centred facility. I became aware of the women's health centre in Windsor through my research and asked the physician in charge if she considered the facility to be women centred. She said it was, and I was immediately taken on as a patient once I had paid the fee to attend. Initially, I was very satisfied with my care; I was immediately given several tests to explore my current level of health, and discovered that I was very low on several



vitamins and iron. I also had a dermatological concern for which I immediately received a referral. I was slightly disconcerted that the facility was purportedly women centred but also took on male patients, and that the director of the centre owned a spa next door. This meant that there were advertisements for various products posted everywhere, and I often felt slight coercion to buy in. I was happy to see a nurse practitioner and doctor, but did sometimes feel that my appointments were rushed.

After two years, I came to see my doctor about cervical pain I had been experiencing. I was told that it was nothing to be worried about and that my routine physical had been normal. I felt largely dismissed. The pain did not go away however, so I decided to see the university health centre again. After an ultrasound, I was told I had a cyst that was likely causing the discomfort. Although I was leaving the country soon, they gave me a copy of my tests so that I could see someone when I moved to the U.S. I was angry. For me, a women centred facility was supposed to listen to its female patients, not rush them out of the office dismissively. For the first time, I truly related to the negative experiences of the women I had interviewed. In conjunction with the other issues I had with the facility (i.e., the fee, the fact that men could attend, and product placement), I decided not to renew my membership.

Clearly, the women's health centre I had attended was not aligned with my personal understanding of what women centred care meant. Prior to undertaking this project, I probably would have described women centred care as a facility focused solely on women, with women doctors available. During my Master's degree in 2005, I was a research assistant for a project related to women's health and fashion. I stumbled upon Hills and Mullett's (2002) article and became immediately interested in the area. It has



now been over half a decade that I have been informed about women centred care, and I have largely subscribed to Hills and Mullett's (2002; 2005) definition during this time. My understanding and interpretation of the constructs and patient issues in this research has largely been shaped by these readings. I do not necessarily see this as a limitation to my analysis, but it is a factor of influence. I felt I should reflexively address my perspective in order for readers to understand how I interpreted these women's stories.

Hopefully, these vignettes give a better sense of who the women were (and who I am), and can relate the women's personal histories back to the larger narrative I am about to tell about the entire group's experiences with women's health centres.

# **Interpretive Phenomenological Analysis**

Having presented my version of the women's individual stories, I will now present the results of the IPA. Smith and Osborn (2003) note that the division between analysis and writing is somewhat fabricated, and rather that analysis is expanded during the writing phase. It should be noted that this was the case here as well; as I wrote up my results, my perceptions and understanding of the themes I had assigned evolved. I had originally asked three fundamental questions: Why did the women initially choose women centred health care? Why did they continue to use it? How did they describe their experiences with women centred care? I attempted to answer these questions in my analysis, and will present the results here.

**Summary.** Based on the step-wise process I employed in undertaking an IPA, there were seven superordinate themes that appeared to varying degrees across the seven interviews: dissatisfaction and mistrust, seeking an alternative, perceptions of care, role of connectivity, defining health services, navigating health services, and role of self-



identity. After some consideration, and in order to give my results a coherent story arc, I will present these themes in four chapters. In the first, *Women's health centres as an alternative to other care*, I will explore the women's experiences with other types of care (i.e., dissatisfaction and mistrust), and the decision to attend a women's health centre (i.e., seeking an alternative). In the second, *Experiences at women's health centres*, I will present the women's perceptions of the care they received at the women's health centre (i.e., perceptions of care) and other important experiences (i.e., the role of connectivity). In the third, *Defining and navigating health services*, I will relate how the women defined ideal women's health services (i.e., defining health services), and the types of behaviours the women engaged in as they traversed the Ontario health care landscape (i.e., navigating health services). Finally, in *Understanding and contributions of "the self*" I will explore the role of the women's identities (i.e., role of self-identity), which contributed to understanding their health needs, and their subsequent behaviours. Figure 1 presents a visual representation of these categories.



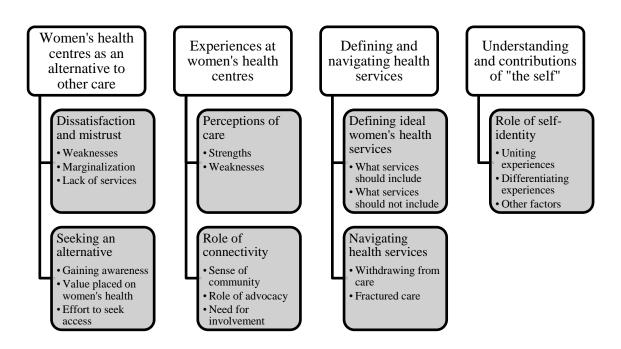


Figure 1. Visual representation of the IPA

Because the findings within each theme were so diverse, I have integrated the findings with interpretations and explanations, using previous research and literature to contextualize my work and presenting each theme as a separate chapter. Each chapter represents a results and discussion section of its own. In the final chapter, I will connect all of these findings across chapters.

Lastly, I will rely heavily on verbatim passages from the women's transcripts while discussing my findings, and must clarify some brief stylistic issues. When the women hesitated, or stopped and started a new thought, I used a dash (i.e., "-") to denote the hesitations. When I left out parts of the sentence, such as if the passage provided too much personal, identifying detail, I used an ellipsis (i.e., "…") to denote that a piece of the text was missing. Although I was inspired by the APA's requirements for quoting of sources, these choices reflected my personal preferences for reading participant passages.



### CHAPTER IV

#### Results and Discussion: Women's Health Centres as an Alternative to Other Care

In this section, I will explore the process of how the women decided to attend a women's health centre. This will involve two major themes from the data: dissatisfaction with and mistrust of previous health services, and the process of seeking an alternative as a meaningful decision.

# **Dissatisfaction and Mistrust**

Even though I wanted the women to focus on their experiences with their women's health centres in the interviews, they could not tell these stories without contextualizing them within their larger health care experiences. Overwhelmingly, the women's stories of their experiences prior to attending their women's health centres (and even after) were negative. The women were generally dissatisfied with and mistrustful of their services, and in some instances angry about what they had experienced. The three sources of dissatisfaction and mistrust for my participants were: weaknesses they perceived of the health care they had received, experiences of marginalization, and lack of services.

**Perceived weaknesses.** The women perceived weaknesses related to three areas: the status of the health care system, the conditions of their services, and the qualities of their providers. With regard to status at a larger "systems" level, Jane noted that, "Patients do not come first, dollars come first." Patient centred care, a term widely used though poorly understood (Stewart, 2001), has been identified as a high priority in Canada's health care system since at least 2007 (Stewart, Ryan, & Bodea, 2011); it is



politically advantageous to assert this status. Unfortunately, patients' perspectives are not often solicited when attempting to discern the patient centredness of facilities, and instead we have largely explored *providers*' perceptions of patient centredness (Law et al., 1995; Stewart, 2001). A decade ago, researchers suggested that there is little evidence to indicate that any of the current definitions of patient centred care matter to patients (Little et al., 2001). However, this issue has rarely been addressed since. The fact that the women in my sample did not find their health care outside of a women's health centre to be patient centred (and were disappointed by this deficiency) suggests that this model may mean something to patients.

Similarly, Jane also talked about the conditions of her services with some frustration:

[My voice] is not heard and it's not considered important. That's why it's not heard and it's really frustrating. And it's also scary because my doctor is in his sixties, so he could retire anytime and then I've got nothing. And what I've got now isn't brilliant, and when he goes, well, I am left with nothing...So you've got to really hope you stay healthy and don't need any help, which is scary. You know, it wasn't really at the forefront of my thoughts when I was in my twenties or thirties, but it is because I'm in my early sixties and so, you know, now I'm kind of more aware of things that could happen and wondering, well, what would I do?

Clearly, Jane felt marginalized by the larger system (i.e., "[My voice] is not heard"), which I will address in the next section of the chapter. However, this passage is also important because it reveals that the women were not just worried about the current state



of their health care, but the future state of health care as well; Jane was not the only woman to wonder what would happen when her aging general practitioner retired, nor to reveal that her age was a significant factor in shaping her beliefs and understandings of her health experiences. Patty, who was 50, said:

Our health services have been in the toilet for eons now. How does that make me feel? Oh, I'm just another one to add to the pile of things that we can complain about. But since we really don't have much control over it, I guess there's no point in complaining. You just deal with it and find another way. So from that standpoint, plus the fact that I'm aging, I'm getting new stuff going wrong it seems like every day, which really sucks... that's not something to look forward to.

Of course, you know, I'm looking to health care more and more all the time. This passage again suggests that the women felt frustrated, distrustful, and weary of their health services in general. While lack of control over their health care was a systemic issue, the passage also reveals that the women tried to cope with the continual negative experiences by attempting to find another way (e.g., explore the option of a women's health centre or clinic).

Many of the women in my sample described themselves as "aging," and almost all of the women discussed aging doctors as a problem. In particular, the issue of their providers retiring seemed very salient. Previous research has indicated that increasingly, aging family doctors are retiring or reducing their practices each year without seeing replacements (MacKean & Gutkin, 2003). For Canada and the U.S., this pattern poses a particular threat; our aging populations have greater health care needs, but we have consistently fewer general practitioners to offer services (Colwill, Cultice, & Kruse,



2008). The concerns of the women in my sample seem to offer support that this trend is continuing, despite the evidence that the number of doctors per capita in Canada has increased in the last five years (OECD, 2011). Notably, the OECD's analysis does not account for the fact that the number of new medical graduates interested in starting a family practice has significantly decreased in favour of specializing over the last couple of decades (Wright, Scott, Woloschuk, & Brenneis, 2004). In Ontario, however, there has been some research to suggest that within the last couple of years, more medical school graduates are choosing family medicine again (Rosser, Colwill, Kasperski, & Wilson, 2010). Unfortunately, exact rates have not been disclosed and this research does not address regional disparities in provider availability. My study points to the need for further research to explore which Canadians, and residents of different Ontario regions in particular, are accessing these new providers.

In addition to the concerns of the older women, it is also necessary to address some of the specific problems the younger women. In particular, they appeared to have specific criticisms for the providers and their training. Sarah said:

The GP made a bunch of assumptions that were not true. She didn't have due diligence and check in with me to see what I believed. She also didn't seem to understand contraception. That was a concern for me. She wasn't familiar with some methods, which was a problem.

Sarah, being of a different age demographic (i.e., 20 to 30 years), had different personal health concerns (e.g., contraception) and thus different criticisms of her services. She continued:



My biggest frustration is the lack of sexual health information given by clinicians, because sexual health needs are one of the most common reasons why women visit health services. And this issue is barely receiving attention in medical school. They spend a day on birth control!

Sarah's criticism was a very specific issue related to her provider and her provider's training. Another young woman also had a provider-related concern. Here is a portion of my interview with Helen (aged 27):

H: Well, my GP is an older male.

B: Right...

H: So there would be times when I would express a concern and he would downplay it or he would think that it wasn't a concern or he would say that it was um, an aesthetic thing and that I didn't need it and things of that nature.

B: Yeah. That seems like a common story, that you weren't necessarily satisfied with some of the care that you received beforehand.

H: No, and I felt that I would have to push a lot or kind of convince him to give me a referral and things of that issue.

Helen's personal health issues, in contrast to Sarah's (and many of the women for that matter), were not sexual in nature but instead more aesthetic. Similar to Sarah, however, Helen felt that it was her provider, specifically, who was not giving her what she needed.

In particular, these issues may have highlighted another "problem" with doctors aging: the younger women felt like their older doctors were not staying abreast of new advances, and could not relate to their specific issues. The implications of this finding are serious; if patients do not believe that their provider is capable of dealing with sexual



issues, they will be less likely to report them (Nease & Liese, 1987), which could put women at risk. These perceived weaknesses may indicate places where we need to improve training of our health care providers. For example, it is largely unclear whether and how providers receive training related to human sexuality. More specifically, it is ambiguous how providers are trained in women's sexual functioning and how to handle complaints related to this health issue (Berman, Berman, Felder, Pollets, & Chhabra et al., 2003). My research seems to indicate that more training may be necessary, particularly in how to handle encounters with women in a way that will make them feel comfortable.

On the other hand, these criticisms also imply that health care providers may simply be out of touch with what their patients want and expect (Rozenblum, Lisby, Hockey, Levtizion-Korach, Salzberg, et al., 2011). In other words, medical education may have had nothing to do with these women's complaints. Expectations are essential to patient satisfaction (Oliver, 2010); in particular, failure to meet patient expectations can lead to dissatisfaction (Marvel, Epstein, Flowers, & Beckman, 1999). While providers generally acknowledge that asking patients about their expectations is important, very few actually do so (Rozenblum et al., 2011). Based on my interviews, it seems clear that the women were not being asked by their provider what they expected and desired, meaning that it was likely difficult for their provider to meet their needs.

These findings point to very specific places for improvement: namely, an improved definition and application of patient centred care, enhanced recruitment of physicians for family practice, improved training for providers in sexual health, and asking patients what they expect out of their encounters with their providers. When general criticisms were given that could not reveal specific places for improvement (e.g.,



that the clinics were simply "a disaster"), they instead revealed important patterns of access to health services. In this case, women largely decided to not seek care with those particular services any longer.

**Marginalization.** As I have already mentioned, one of the major consequences of the weaknesses perceived by the women was that they experienced marginalization. Marginalization is a process where people are relegated to the fringes of society based on aspects of their identity and activities (Hall, Stevens, & Meleis, 1994); it is both exclusionary and isolating (Dodgson & Struthers, 2005).

In this sample, the marginalization experienced by the women was systemic, both general and specific, and in some instances internalized. More generally, Jane believed that," [My voice] is not heard and it's not considered important." Similarly, Cheryl related that, "When I was younger, I mean...I didn't feel that I had any rights." Patty also said:

Nine times out of 10, they treat you like the masses. They're going to solve the problems they can. The problems they cannot solve, they push off to someone else to solve. It's the only way they can get through their day, okay?

Although these smaller passages lack context, the point is that they appeared time and again, peppered throughout the interviews as the women related their experiences with the health care system. The consistency with which they appeared revealed that the marginalization was so systemic that it had largely become synonymous with accessing services. Some of the women did have more specific examples of marginalization, however. Sarah said:



It's hard...I guess the fact that I'm young has been used to make judgments against me. For example I told my doctor that I wasn't using condoms anymore and I received this whole lecture about the dangers of not using condoms. I mean I was with my partner for three years and I said, "I know, I understand the risks." But she then tested me for STIs, which I am fine with, but she didn't actually tell me. So she's like, "Take these vials to the lab," and made an assumption about me. Being young, some people don't take their health as seriously so there's this

This passage is indicative both of a perceived weakness with Sarah's health care provider (i.e., the fact that she made baseless assumptions), and of how Sarah had been marginalized by her provider to the point that she wasn't even told what type of test was being conducted on her body.

judgment about the level of risk you're engaging in by virtue of your age.

In some instances, the marginalization was so deeply entrenched in the women's narratives that they seemed to blame themselves for their negative feelings. For example, in the following exchange with Laura, she discussed her dissatisfaction with the many services she had accessed (e.g., mental health provider, sexual assault clinic, general practitioner, and other specialists), which seemed to reveal internalized marginalization:

L: I'm sort of afraid at this point. It's almost like the cards are stacked against me but you think, "No, no it's not you." But I don't know.

B: Well, I mean you have your own life experiences and story and I think that you have to take all that into account and you can't blame yourself for how you feel about things.



L: Well, I was. I wish – I am. I am. I'm totally feeling like, I don't know – I have to kind of – I am and I'm not, I'm fighting that, you know. So maybe I'll – yeah, do you sort of get that picture then that there's no continuity of services and I am marginalized at any rate?

This passage seemed to indicate that Laura blamed herself for her negative experiences with the health care system. The marginalization the women experienced was thus not just affecting their perceptions of the care they received, but also their well-being. As such, the women's experiences of marginalization were similar to other research showing that in the health care setting, marginalization contributes to feelings of isolation, having limited options and power, and the feeling of being silenced (Leipert & Reutter, 2005).

Marginalization has become a particularly important construct with important implications for the provision of health care (Tiedje, 2001). As I detailed in the introductory chapter, women and other vulnerable groups have experienced a troubling history of marginalization within the health care system, often leading to negative outcomes. For example, research with Aboriginal women has shown that marginalization can contribute to feelings of disrespect and being silenced, which ultimately leads to mistrust of the entire system (Dodgson & Struthers, 2005; Prodan-Bhalla, 2002). Recent marginalization research has largely focused on women with multiple vulnerabilities, such as class, race, age, or all of the above (e.g., see del Bene, 2010). On the other hand, in my research specifically, the women were largely privileged in many ways other than their gender. This privilege may have contributed to the outcome I witnessed here; when these women felt marginalized by the system, they simply sought an alternative (i.e., a women's health centre). The real concern is what would happen to women without other



options. For this reason, researchers have articulated the need to "give voice" to vulnerable populations; only in this way will we understand how marginalization impacts individual women and their experiences with health care (Dodgson & Struthers, 2005; Meleis, 1996). My research supports this assertion.

Lastly, one other important finding is that even with the experience of being marginalized by health services, the women did seek alternatives. This suggests that women may be resilient, and work diligently to have their voice heard within their services. However, I can only comment about this resiliency in relation to women with the resources to seek other options, as I did not interview many women with multiple vulnerabilities. This is an area for further research.

Lack of services. I have already alluded to the notion that the women were afraid of what would happen when their providers retired. In some instances, however, it was more than just a future concern, but instead a current problem. For some women, the only reason they had even arrived at a women's health centre was because there had appeared to be no other options; they could not find a general practitioner who would take them on. For example, Julie had moved three years ago, could not find a doctor in her new city, and had accessed the women's clinic for basic health needs and the emergency department for her kids:

I have gone to the emergency department for my kids over the years. But it does cause me stress to see on the news all the time about how the wait times are getting longer and longer and people are dying in the waiting room, and people are going undiagnosed, and you know, they die waiting for treatment, and it's like, what if I have to be on the waiting list for something one day, or what if my



children? Yeah, it is still stressful, even though I solved one problem (with the women's health centre) but the whole health care thing is worrisome to me. Like, it's not good. So I mean, not only do a lot of women don't have doctors, but they don't have access to a women's clinic either.

Julie's lack of options, and lack of a general practitioner, meant that she had sought out the women's clinic, and used the emergency department for her children. It was clear, however, that she wanted something more permanent.

Patty was another woman without a general practitioner, noting, "I haven't [had one] for a few years." She did not give the reasons for her lack of a general practitioner, but noted she had used the women's health centre to get by. Sarah had also been without a general practitioner at times, albeit for different reasons entirely:

Okay, I came to Canada in 2005, so I was a junior at [the University]...And after I graduated, there was a six-month period where I lost my coverage....But in the meantime I was accessing care at a community health centre, and then also a sexual health clinic and again for birth control.

Many of the women in my sample did not have a general practitioner and could not find one, and often went without care as a result. This means that those without a GP were overrepresented in my sample; in Ontario, more than 70 percent of the population has a family physician (Hutchison, 2010). The fact that my findings are not completely generalizable to all women in Ontario does not mean that these findings do not matter; they simply point to the experiences of a minority group in our province. Furthermore, although I have not disclosed the exact locations of each woman, they do come from several different regions in Ontario. Because different regions have varying levels of



accessibility, we need to consider the representativeness of their experiences. However, research has also shown that across North America, patients often cannot access health care in a timely and effective way (Howard, Davis, Anderson, Cherry, Koller, et al., 2005; Richardson & Hwang, 2001). This issue is sometimes explained by the inability to find a doctor (MacKean & Gutkin, 2003). Most recently, Canadians rated the availability of family doctors the most poorly among all services available to them (Canadian Medical Association, 2011). At the same time, Canadians were more likely to have complained about quality of their health services or wait times in the past year rather than access to health services (Canadian Medical Association, 2011). This statistic in particular may explain the subsequent care seeking behaviours of my participants. That is, the women had other options to consider (e.g., a women's health centre), and were not completely without available services. Even though their lack of access to a family doctor was problematic and pushed them to seek an alternative, the important outcome is that they *did* seek an alternative.

All three of these sub-themes (perceived weaknesses, marginalization, and lack of services) resulted in the women becoming dissatisfied with their services and mistrusting the health care system. I had not been looking explicitly for themes related to dissatisfaction and mistrust, but when they emerged, it was not particularly surprising. I may, in fact, have been primed to explore these constructs based on the current literature on patient perspectives. In the last two decades a large body of research about patient satisfaction has been amassed (Eriksson & Svedlund, 2007). There are a couple of reasons for satisfaction's prominence in the health literature; first, it has been identified as a key outcome in health consumer research (Linder-Pelz, 1982), and second it is



largely considered to be an important indicator for quality of health care (Williams, 1994; Williams, Coyle, & Healy, 1998). However, evaluations of research related to patient satisfaction have been less than favourable. Methodologically, the tools used for measurement of satisfaction have been criticized for their lack of veracity (Hankins, Fraser, Hodson, Hooley, & Smith, 2007), and theoretically there is no real foundation for why satisfaction matters; in part, we might only continue to explore satisfaction because no one has thought of a realistic alternative (Mead, Bower, & Hann, 2002). In the face of these criticisms, it has been suggested that we move to studying dissatisfaction (Eriksson & Svedlund, 2007). In particular, examining the reasons for dissatisfaction would indicate ways to improve quality of care (Williams, 1994; Williams et al., 1998), an important outcome that satisfaction cannot address.

Similarly, trust and mistrust have recently been identified as essential variables in the study of health care. Much of the research that does exist on trust/mistrust is presented in terms of how trust in health services impacts the utilization of these services by racialized groups specifically (e.g., see Benkert, Hollie, Nordstrom, Wickson, & Bins-Emerick, 2009 or Schwanke, 2002). While trust has been identified as a potentially important indicator in understanding all patients' utilization of health services (Pearson & Raeke, 2000), there is a lack of empirical evidence to suggest exactly how *mistrust* impacts this process (LaVeist, Isaac, & Williams, 2009). In this case, the causes of dissatisfaction and mistrust highlighted areas of improvement for our current health system and unveiled patterns of access. In other words, this research supports the notion that dissatisfaction and mistrust are important indicators of quality and the navigation of health services.



# Seeking an Alternative: A Meaningful Decision

Based on these interviews, I believe the decision to attend their women's health centre was a meaningful one for the women, and not just left to chance. While the dissatisfaction and mistrust with previous health care was clearly a major contributor, other factors in the decision making process included how the women actually heard about the women's health centre, the value the women placed on women's health, and the effort it took to actually access the women's health centre. In other words, the decision was meaningful to the women and required careful thought.

**Gaining awareness.** Each woman became aware of the women's health centre she was attending, or had attended, in various ways. Most had happened upon their facility by "chance" or word of mouth. However, they had largely put themselves in positions to hear about these facilities from similar services, people with ties to health care provision, or those who were like-minded (i.e., valued women's health). For example, Laura reported, "Well, I had heard of it, as we said, from the champion nurse practitioner, and – now how did I come to find out – from the sexual assault clinic there." Because she was already accessing services that were focused on women, she had a means of hearing about other similar services. On the other hand, Patty said:

Oh gosh – I've been serving on committee with the hospital for years, and we had a representative from the women's health care centre join our committee. I think that's probably the first time I heard about them. And she was describing some of her services, and when she mentioned that they do paps, I thought, "That I've got to check out." And that's where that was really useful for me.



Again, even though Patty had not been actively seeking a women's health centre, she had been involved in the health care setting already, giving her an opportunity to hear of these services. Similarly, Jane said:

Oh well, when we moved to the area I made a friend with a woman who trained as a nurse... And so we were talking about menopause, and she told me that there was a group – not a group – sort of a course, over several weeks, like an evening at a time, and I think I kind of remember it was a six-week, or something like that, program. And each week we covered a different aspect of menopause, and so she told me that this existed and so I signed up for it, and then I started finding out about all the other things that were available, like the newsletter, and the library, and the fact that there is a nurse practitioner and that they had different groups... But I kind of, once I knew that the centre was there, I found it was easy to find out what else they were offering. I think I was just really fortunate that I made friends with this woman and she told me that it exists, and I then kind of in turn keep telling everybody that I meet that it exists.

This passage highlights two major points. First, while Jane came to the centre by "chance," similar to the other women, her point of access was through a tie to the health care field. Second, it is clear that Jane herself had some interest in "women's health" and valued health care that would treat her needs specifically. This value certainly contributed to her arrival at the women's health centre beyond simply having a contact in the health care field or knowing someone with like-minded values. I will address this notion of valuing women's health in the next section.



Of the seven women I interviewed, only one woman happened upon a women's health centre fully by chance. Helen said, "It was actually my fiancé who goes [to school] and he thought – he saw a sign for it and he knew I had gone to one in [my other city], and I was looking for another facility." In Helen's case, it was her boyfriend who simply saw the centre advertised, and told her the service was available. On the other hand, Helen was also looking for a facility of this nature, meaning that she placed some value on this type of care. This would have likely influenced her boyfriend's awareness of advertising directed at women's health care consumers.

That these women heard of a women's health centre at all was often driven by them being in an environment conducive to learning about such a facility. These women either had ties to the health care industry themselves or awareness of someone who did, and perhaps as a result, had high levels of health literacy. Health literacy is defined as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health" (Nutbeam, 1998, p. 358). It has been implicated in a variety of health outcomes and utilization of health services, with more of a focus placed on low levels of health literacy and poorer subsequent outcomes (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Lindau, Tomori, Lyons, Langseth, Bennett et al., 2002). I believe that the women's high health literacy and connections to the health care industry influenced their decision to change facilities when they were dissatisfied with their previous services. This finding supports previous research suggesting that health literacy contributes to patients being more informed and stronger consumers of health services (Levin-Zamir &



Peterburg, 2001). However, little research exists on the pathways between health literacy and patient participation (Ishikawa & Yano, 2008), and so more research is required.

The high health literacy of the women in this sample could also be an indicator of three other issues. First, it is possible that this outcome is an indicator of sampling bias, and that women with higher health literacy were more likely to participate in a study about women's health. Second, it is also possible that women's health centres in Ontario are populated with highly health literate women. If this is the case, it may be that women's health centres are not doing a good enough job of advertising their services to women of various backgrounds; the clientele of women's health centres would then consist of large numbers of women with high health literacy, and women with low health literacy would be underserved. Clearly, this is purely a hypothesis and requires further research for support. Yet research has indicated that some women centred services are underused (Johnson, 2001), and that low health literacy negatively impacts a woman's ability to navigate the health care system (Sheih & Halstead, 2009); in other words, there might be a connection between underuse and the ability for women with low health literacy to attend. Unfortunately, almost 60% of Canadian women have inadequate levels of health literacy (Canadian Public Health Association, 2008), making this a salient factor. Finally, a third explanation is that attending a women's health centre actually improved the women's health literacy. I did not explore this particular issue with any detail, but is a potential benefit of attending a women's health centre. My findings suggest that further research is needed to confirm whether and how women's health centres are reaching women from multiple backgrounds with their services, and how these services improve women's health literacy.



The value placed on women's health. Many of the participants valued women's health and facilities that served this need, and several women seemed to have been actively seeking this type of facility. These values and behaviours contributed to the women moving from simply being aware of the women's health centre to actually attending it.

All of the women conveyed that their health and health care services were areas of concern and focus. For example, Jane said:

Well, as I get older it's much more important than it used to be when I was younger, and so I am very concerned about the situation in our area, which is that a huge proportion of people don't have a GP, and our women's health centre has been really touched very badly with the new hospital being put up and some financial difficulties that they have.

In this case, Jane's age was certainly a determining factor in making health a priority. Clearly, her concerns also extended beyond her personal health to other people in her community. The younger women also cared about these issues. Sarah noted:

Unfortunately, I don't think women's health is a priority in Ontario but it needs to be. We're not going to fund Planned Parenthood in Ottawa because we want to fund health literacy instead. I get that the health education system isn't meeting the need to promote health literacy, but sexual health information is limited. It's critical to fund these services!

For the most part, Sarah was equating sexual health with women's health, a view not shared by older women in the sample. However, it was evident that Sarah wanted



women's health to be a priority to our government, and that she cared about services for all women.

Conversely, some women did not convey the value they placed on their health by saying so outright. For example, Patty said:

That was sending the message that women's health doesn't matter. You know, we've built this state-of-the-art hospital, which went well over the budget, which is just not able to offer the services that they offered, but we do have a very top-heavy management, and that's okay, but services for women don't matter. So we keep all these "fat cats" who are mismanaging our money and at the same time we're getting rid of nurses in the hospital and we're decimating the women's health centre. It was kind of – it's not a big thing, but it was sort of insulting, the attitude that's basically saying, "We don't really care about your health."

Patty did not directly say that women's health was a priority to her, but indicated that it was an insult that women's health was, in her estimation, not a priority to others in the health care system.

This value the women placed on their health translated to care seeking behaviours. As I already mentioned, Helen noted that she had been "looking for another facility" that focused on women; it was something she already valued. Similarly, here is an exchange with Jane that highlights how accessing a women's health centre was probably already a personal value for her as well:

B: Do you feel because of where you were in your life – that you wanted to seek out further information for menopause and whatnot – that that led you to a



women's health centre? Or do you think that you would have sought that on your own out at any point in your life?

J: I think I would have bumped into it... I think I would have found out anyway, it was important. It just might not have come as quickly as that. And I think that there's quite a good community of women in the area, so I imagine that I would have found out from talking to one of the women, because we tend to share information about things that are going on in town and so... I am pretty confident I would have found out. This just happened much quicker, and it was really at the appropriate time.

For Jane and others, they believed it was only a matter of time before they came across a women's facility, because it was something they already desired. Of course, for some women, it may not have been that accessing a women's health centre specifically was important, but rather that they just cared about health care in general. Sarah said simply, "Yeah, there's a fair amount of thought that I place on my health care services." In other words, it was a conscious effort when and where she sought her services.

Previous research has also indicated that women value women's health clinics and women-friendly care, and that these modes of care are preferred to "regular" services (Peters, 2010). While this notion would potentially bode well for women's health centres (i.e., they would attract more patients), there are also important negative implications. That is, women prefer these services, but if cutbacks continue, women friendly services may become difficult to access. If women prefer women friendly services to the point where they would rather go without care than access traditional services, women's preferences may ultimately impact their decisions to seek health care in a negative way



(Peters, 2010). Further research is necessary to understand how women's values impact their health care seeking choices in Ontario.

The effort to seek access. I have called this larger theme "Seeking an alternative: A meaningful decision" arguing that the decision to attend the women's health centre had some type of meaning and required careful thought. One important piece of this decision was that the women chose the women's health centre, often in spite of perceived obstacles being placed in their way or having access to other primary care. In other words, the women put in extensive effort to attend a women's health facility. Julie related the difficulty she faced in this manner:

It was really confusing to access. It's really not public access, you know, because [it is] such a small little town, and you would never even really think that there would be a women's clinic there. And then trying to get to find the number for it was hard, because you had to call the...hospital, and then they transferred me to somebody who had no idea what the women's clinic was doing. It had nothing to do with the women's clinic, so then they had to transfer me to another person, and it was really hard to access. And if you don't know about it, then there's no way you could really find information about it.

Ultimately, this passage is indicative of two major issues. First, Julie was determined enough to attend that she persevered even through the obstacles put in her path. This experience was similar to other women. Second, it highlights an issue that may be more problematic; the women believed that the women's health centres they attended were not well advertised or known. There were also other indications of an effort given by the women to attend. Helen said simply, "I wouldn't just settle." She had been in search of a



women's health facility, and as a result had actually attended two such centres in both of her locations. Cheryl seemed to agree that an active effort was required to have access to women's health services saying, "I don't think the girls will have women centred health unless they have women willing to fight for it." While this quote does not specify the effort that she had expended personally to have access to women's health services, it does indicate that she thought an effort was required.

My findings support research suggesting that women often face barriers when trying to seek care, including those that are social, institutional, and provider related (Rodriguez, Quiroga, & Bauer, 1996). Rose (2007) has suggested that with changes to today's health care system (i.e., the shift to technology rather than embracing holism), people are forced to take personal responsibility for their health in order to gain access to the services they need; my findings also support this belief. Whether or not this approach is preferred by patients, however, will need further examination.

While many factors will contribute to whether or not women eventually gain access to services (e.g., their gender, class, race, geography, etc.; Hankivsky, 1999), another factor here seemed to be a willingness to pursue options despite being faced with barriers to access. It has been suggested that Canada's health services are designed for middle-class English speakers, and that minority women have a more difficult time finding culturally competent, responsive, and accessible care (Anderson & Reimer Kirkham, 1998; McGibbon, Etowa, & McPherson, 2008). My sample of women was largely privileged in important ways that allowed them to access health services relatively easily. They also had high health literacy, a factor known to contribute to the successful navigation of health services (Levin-Zamir & Peterburg, 2001). It is not surprising, then,



that these particular women overcame multiple barriers to accessing their care. On the other hand, if these largely privileged, health literate women faced challenges in accessing a women's health centre, we should have serious concerns for other vulnerable populations in Canada. For too long, we have focused on "women" as a single category without understanding how various vulnerabilities impact women's health care behaviours. Further research is necessary to understand how this process unfolds when all types of women attempt to access health services.



# CHAPTER V

### **Results and Discussion: Experiences at Women's Health Centres**

Now that I have related how the women sought women's health care centres as an alternative to other care they had been receiving, I will explore what they experienced following this decision to attend. I will also introduce how these experiences contributed to the women staying at the centre or leaving their facility. This will involve two major themes from the data: perceptions of the care received at the women's health centres, and the role of connectivity.

### **Perceptions of Care**

In order to fully relate what the women experienced at the women's health centre they attended, it is important to discuss both perceived strengths and weakness of their care.

**Strengths.** One of my fundamental questions was why women continued to use women's health centres, or not. I was interested to see if the women believed that there was something specific about women's health centres that would set them apart from other types of facilities. All of the women reported strengths of their women's health services that fell under the following broader categories: the mandate of the women's health centre, the characteristics of the health care providers, the services offered, and the overall quality of the women's health centre. In many instances, these strengths could only be experienced at a women's health centre. However, some of these strengths could have been articulated about any health care facility.



Several of the women addressed the larger mandate of their facility as a strength of the care they had received. For instance, when asked to detail some strengths Laura said, "Yeah, just their woman focus," while Helen said:

Women, um, have always been different from men. We have body issues and things of that nature. But I think they appreciate that. In terms of specific illnesses like things leading to cancers that women are infected by.

These strengths were specific to services for women, and support other research suggesting that women's health centres are appreciated by women because they deal with women's issues specifically (Peters, 2010). One of the major advantages of women's health centres is the attention paid to gender differences (Meadows, Thurston, Quantz, & Bobey, 2006). Previous research has indicated that women tend to prefer clinics that focus on women's health (Lentz, Ayala, & Eckert, 2006; Phelan et al., 2000); however, much of this research focuses on gynecology settings. My findings suggest that the women also understood their health needs to differ from men beyond purely physiological processes to include aspects of socioemotional health (e.g., body issues). This corroborates previous findings suggesting that sensitivity to women's "issues" as a larger goal is valued by women patients (Lentz et al., 2006).

On the other hand, the women also perceived strengths that were not necessarily focused on women. Julie said, "At this particular women's clinic, I do get the feeling that it is patient-centred – from what I've experienced so far." In other words, this was a strength of the facility that could have been perceived anywhere, and not just at a women's health centre. While there is little evidence to say whether any of the existing definitions of patient centred care matter to patients (Little et al., 2001), within the last



decade there has been at least some indication that patients appreciate certain aspects of this approach to health care (Coulter, 2005). My research not only suggests that patients have some understanding of what "patient centred" means, it also indicates that patients see this approach as a strength. The fact that the women perceived these two aspects of their health centres as assets is an important contribution to the literature. It gives value to the mandate of women's health centres, and affirms that funding these facilities is essential. That is, the services rendered at a women's health centre are appreciated and important.

Many of the women also described specific characteristics of the providers they had access to at a women's health centre as a strength. For example, at the health centre Cheryl attended, she largely had access to a nurse practitioner who she vastly preferred to her doctors both outside and within the facility. She said:

The nurse practitioners were good because they listen to you, they, they aren't – they don't help too much just to help with you, so it's more like a dialogue, so I really did prefer the nurse practitioner over the doctor in most cases.

This theme of appreciating the nurse practitioner, and even a preference for a nurse practitioner, was something I saw across many of the women's experiences. While patients tend to show high satisfaction for both doctors and nurses, it seems that the type of provider preferred may depend on the context within which the care is being given (Laurant, Hermens, Braspenning, Akkermans, Sibbald et al., 2008). Patients have been shown to prefer doctors for medical aspects of their care, but often prefer nurses when seeking educational support (Laurant et al., 2008). Some literature has also shown that a majority of patients do prefer a nurse practitioner to a primary care physician (Williams



& Jones, 2006); however it is largely believed that they are preferred because nurse practitioners tend to spend more time listening to patients and their needs, rather than being objectively "better" in comparison to doctors (Williams & Jones, 2006). This appeared to be the case for these women as well. They appreciated it when the nurse practitioner took the time to listen because they felt like a person rather than a medical issue.

Although there is some indication that patients largely prefer nurse practitioners because of the time they spend with their patients, this is not the only factor contributing to high satisfaction rates. Research has indicated that nurse practitioners also deliver quality care that is at least equivalent to primary care physicians (Lemley & Marks, 2009). The fact that my research supports the competency of nurse practitioners is valuable given the current state of literature related to nurse practitioners. First, there is an unfortunate paucity of research related to nurse practitioner-led clinics (Hayes, 2006). Second, this lack of research is particularly problematic given the current state of health care in North America. Namely, the increased need for prevention and chronic disease management is changing the face of primary care, yet we are facing a shortage of primary care physicians to provide these services (Association of American Medical Colleges, 2007; Bodenheimer, Chen & Bennett, 2009; Lemley & Marks, 2009). As a result, nurse practitioners are often filling a critical need for health care providers in underserved areas, such as rural or impoverished communities. This point is also particularly relevant for women's health centres; because they are often under-funded, many women's clinics rely on nurse practitioners for support. Further research is needed to understand patients'



health outcomes in nurse practitioner-led clinics, particularly in terms of access and utilization of services.

Additionally, some of the women discussed the doctor they had access to at the women's health centre as a strength. One perceived strength mentioned by several women was the fact that their provider was also a woman who could relate to their issues. For example, Helen had sought out a women's health centre for a health issue that was more aesthetic, saying:

Well it was my situation with a female doctor and a female nurse that was good. And I found that was really helpful because the doctors that I'd been seeing before were mostly male and I didn't feel that they could relate to that sort of condition.

Common sense might tell us that women doctors are largely better equipped to deal with health issues that separate women from men (i.e., those related to our reproductive organs); this passage is interesting because it defies that expectation. This was a health concern that was not woman-specific; acne scarring is a health issue that affects both men and women, even if beauty standards do differ by gender. However, Helen still felt that her concerns were better understood by a woman, a theme I saw across many of the interviews.

Another important characteristic of the providers themselves included their knowledge of women's issues. Cheryl noted:

You would go for women's health issues, pregnancies...um, painful periods or something of that nature, or when you are in the beginning of going into menopause. So that was the kinds of weird stuff happening that you just really



needed to talk to somebody who knew. All the doctors were women that I saw, and it made it more comfortable to talk to them.

While this strength is also tied to the doctors being women, it highlights the perception that women would be more knowledgeable about health issues related to a woman's physiology. According to the literature, it appears that many women prefer female providers, particularly for pelvic examinations (Schmittdiel, Selby, Grumbach, & Quesenberry, 1999; Yanikkerem, Ozdemir, Bingol, Tatar, Karadeniz, 2009). Yanikkerem and colleagues also suggest, however, that gender is largely factored into the type of information women are seeking at any given health care encounter, and the way that information is imparted. In particular, during a gynecology exam, women can feel uncomfortable and embarrassed (van Dulmen & Bensing, 2000); as such, they may prefer to speak to another woman. Unfortunately, less research exists on women's gender preferences for their provider outside of reproductive health. In this sample, it appears that the women preferred a female doctor even when discussing issues that were not women-specific. One consideration may be that women physicians generally take more time with their patients, ask more questions, and are more positive (Hall, Irish, Roter, Ehrlich, & Miller, 1994), which may create a more favourable health care encounter for patients (Roter & Hall, 2001). These physician behaviours also appear to be more aligned with what the women in my sample desired from their providers. Future research will need to examine the reasons why women might specifically prefer female physicians.

Lastly, with regard to provider-specific strengths, some of the women discussed their provider's approach to dealing with patients. Sarah said, "No one's judged me at the women's health facilities. I was judged before, but that was with a family doctor."



Meanwhile, Jane said, "I'm part of the decision making about what needs to be done, and that it would be about that woman – and not about money or the big ego of some doctor."

Notably, feeling judged and a lack of respect had been weaknesses of other care the women had received prior to accessing a women's health centre, meaning that their women's health centres were making up this void. Research has largely indicated that women as a group tend to want a collaborative relationship with their provider and respect for their self-expertise (Bean-Mayberry et al., 2003; Bottorff et al., 2001). However, respect for patient experiences is also an important aspect of a patient centred mandate (Mead & Bower, 2000; Stewart, 1995) and family centred mandate (Institute for Patient and Family Centered Care, 2012), making it a principle that seems to be essential to quality care in general. My research is important because it largely supports these findings and also suggests another important area for research: the experience of judgment (or perceived judgment) by providers and how this experience affects women's utilization of health services.

In addition to seeing the centres' mandates and providers themselves as strengths, the women also discussed the types of services available. When asked about what she appreciated about her women's health centre, Patty talked about how she had previously experienced painful physicals, but how these were painless at the women's centre. She said, "I was very focused when I found out that they did paps. That was sort of a very specific need of mine. So I didn't really have to access anything else."

The experience of pain during a pap test can be common, particularly among women who are no longer sexually active (Hoyo, Yarnall, Skinner, Moorman, Sellers et al., 2005; Taylor, Yasui, Burke, Nguyen, Acorda, 2004). This experience of pain has



important implications for subsequent care seeking behaviours; it may be one reason that women do not adhere to pap smear screening, and as such may put women at risk for invasive cervical cancer (Hoyo et al., 2005). Addressing the issue of painful and uncomfortable pap smears (both in the physical and emotional sense), and the speculum (i.e., the most common tool of this discomfort during a pap smear), have a long history in the Women's Health Movement (Kapsalis, 1997). Advocacy efforts of the Movement included reclaiming women's bodies for themselves, and promoting vaginal selfexaminations (Kapsalis, 1997) as a means of reclaiming some of the power taken from women in the process of undergoing a gynaecological exam. However, the role of pain in women-specific care seeking behaviours beyond pap smears has not been adequately addressed in the literature.

Pain has also been identified more generally as a variable that significantly impacts care seeking behaviours (e.g., Andersson, Ejlertsson, Leden, & Schersten, 1999; Mortimer & Ahlberg, 2003). Research for pap tests specifically shows that pain is an important factor in determining care seeking behaviour (e.g., see Taylor et al., 2004). However, others report that pain does not play a role (e.g., see Yu & Rymer, 1998). Peters (2010) has reported that one of the major reasons women seek women's health centres is to experience a safe environment; this notion of pain-free services is likely related to this desire. In the U.S., one of the essential aspects of women centred care has also been identified as the absence of both materials and attitudes that could be considered threatening or inappropriate to women (Milliken, Freund, Pregler, Reed, Carlson, et al., 2001). It seems that the tools or implements of female-specific procedures that contribute to the experience of pain, such as speculums and mammography machines,



could fall under this principle. In this case, the lack of these threatening materials and experiences was considered a strength of a women's health centre.

Unfortunately, little research currently exists examining the specific methods that women's health centres employ during examinations and whether this was an explicit factor in attracting women to use services there. This study contributes to the literature by confirming that the experience of pain during women-specific procedures (e.g., pap smears) can affect women's care seeking behaviours. That is, at least one woman sought pain-free services, and continued to use women's health centres because they were painfree.

Other women's health services were praised for being wide-ranging and forward thinking, particularly in relation to menopause. One of the most commonly reported strengths, however, was the fact that the women had access to information specific to women. For example, Jane said:

They used to have a newsletter, which was sent to a phenomenal number of people, and in it one of the things they always kind of talked about was the fact that they had library day, and they talked about their new additions, and there was a paragraph about a breast cancer walk, and it's about so-and-so, and then they used to talk about what kind of programs they're offering, and what outreach they're doing and stuff, so that was a really good way to spread the information. And these newsletters were also available in strategic places in town, so even if you weren't on the mailing list you could still pick it up. But with the cuts they made they haven't got anyone to create the newsletter and they haven't got the postage to send it.



The desire for knowledge and information about women's health was a theme I saw across the women's experiences. This finding did not seem surprising; the desire for women's health information is highly related to receiving primary care that is focused on women, which I have noted is valued by women. However, previous research has suggested that when discussing their specific desires related to health care providers, women may not actually distinguish between general medical knowledge and medical knowledge unique to women (Houle, Harwood, Watkins, & Baum, 2007). I believe that the high health literacy of my participants may be one reason that these women did make such a distinction. Ultimately, my findings offer important insight into the desires of women in the primary health care setting (i.e., that they do want women specific knowledge and rate their providers based on this criterion).

Finally, the last type of strength women noted was in the quality of their services at women's health centres. In most cases, when the women discussed quality they did not target specific services, but kept their praise more general. For example, Laura praised her provider, saying, "She was a genius, she was exceptional." She also reported, "I went for [my] physical and was blown away by the quality and the level of services, which was comprehensive. And just by the quality of care, it was just so respectful and thorough."

Weaknesses. Having expounded on the strengths my interviewees perceived of their women's health centres, I now turn to the weaknesses. It was not surprising that the women felt that there were limitations to the care they had received at a women's health centre; they had also noted many limitations to other types of health care they had received outside of these facilities. It is worth noting, however, that the weaknesses described here were quite different. For example, prior to attending a women's health



centre, the women had discussed weaknesses such as: not being heard, having a lack of control, seeing their clinics as a disaster, and experiencing judgment from their providers. In contrast, at the women's centres, the women largely wanted more of everything their facilities had to offer; the centres were seen to offer quality services, but not enough of them. This suggests that women's health centres may be qualitatively different from other types of health care. In this sample, the women perceived weaknesses in four major categories: provider-specific weaknesses, limitations to the services available, not living up to a women centred mandate, and not generating awareness and/or accessibility.

Throughout the interviews, many of the women were critical of their providers, although this was largely in the context of the health care the women had received outside of the women's health centre. In fact, only one woman mentioned a criticism of a provider at a women's health centre. Laura had been seeing one nurse practitioner at the centre, but when they changed to a different person, she had the following to say:

And I met with her once and I didn't have a good impression of her at all. So, I didn't have a good feel and who knows why these things are and sometimes maybe it's just because you have such a good rapport with one person, that the next person is a hard act to follow. So, um, I haven't really – I don't know – I haven't really met with her again; I haven't gone to the clinic.

Although Laura's criticism was not related to the nurse practitioner's knowledge or skill, the fact that their interaction was not optimal is still important; health providers' interpersonal skills are essential to quality care (van Zantem, Boulet, & McKinley, 2007). The passage also indicates that Laura desired some continuity to the provider she saw, something I heard in most of the interviews. Unfortunately, Laura felt that she did not



experience provider continuity at the women's health centre, and the outcome of her frustration with her provider is telling. Based on her perceived negative, or even just neutral, interaction with the nurse practitioner, Laura did not attend the women's health centre again.

In addition to provider weaknesses, several of the women reported that the limitations to the services available at their women's health centre were problematic. In other words, the women wanted even more than the centres could offer. For example, Cheryl disliked that she could only go for issues that were specific to women:

When I was really sick before I had a doctor, you know, I went to the Women's Health Centre – but you only could go for women's health issues. Um, so, I couldn't go for everything, but I wouldn't go to a walk-in clinic, so I had a naturopath and the Women's Health Centre.

Potentially, this passage could also been seen as a criticism of the mandate of the centre (i.e., adhering to gender and sex analysis, and only offering services for issues that separate women physically from men). However, I chose to discuss Cheryl's experience in the context of limitations to services because it does address a service she was not able to access. It appeared that the women wanted to be able to take care of all of their health needs, and not just ones for their reproductive organs, at one place. The issue of whether women's health centres offer comprehensive and inclusive care is not new; two decades ago, research indicated that services offered at women's health centres were not necessarily all-encompassing (Lundy & Mason, 1994).

Jane also had serious criticisms of the services available. In the following exchange, Jane addressed some of these concerns:



J: And the other thing about the women's health centre is that we have – [our city] has one of the highest proportions of seniors in the population cities in all of Ontario. Well, the women's health centre isn't really able to do anything for the aging women. There's all kinds of health issues as you get older. Like, when women get to be 70, 80, there's all kinds of health issues and they're not doing anything – nobody's doing anything.

B: I think you mentioned in fact that there aren't programs available at the current centre because they only do anorexia and breastfeeding. That doesn't really speak to you.

J: Yeah. They're focusing on young women and that's very needed, and I'm not saying they shouldn't be doing it, but I certainly feel invisible. That's kind of like saying, "Okay, we're able to do something for the women at that end of life, but we're really not doing anything for women at the other end of life, and we're not doing anything for the women in the middle!" Like the women in their 30s and 40s. Nothing's being done. Yeah.

Jane was not alone in this criticism. Several of my interviewees felt that the services were targeted at specific groups of women (e.g., pregnant women). The women with criticisms of this nature were largely older, feeling that the women's health centres were targeting women of child-bearing years. This issue was also identified as an area of concern in the mid-1990s, with researchers reporting that women's health centres often seemed focused on the reproductive needs of women of child bearing years (Lundy & Mason, 1994); it seems that this may continue to be the case.



Another perceived weakness, and one that I have alluded to already, was the notion that the women's health centres often did not live up to a women centred mandate. I was hesitant to include this theme; several of the women had never used the term "women centred," and I did not want to put my own values in the minds of the women I interviewed. That is, if the women did not need to think of their facilities as women centred, or simply never had, I had to respect that they perceived their women's health centres differently than I did. However, a few of the women had been aware of this terminology, or had been able to articulate that women centred care was valuable. It is the responses of these women I looked to in addressing whether the women's health facilities had lived up to any women centred mandate. For example, Julie had one mandate-related criticism that was tied to the lack of availability of services at her centre. She said, "It's not necessarily women centred because you can't go there [for pap smears] if you're a woman over 26." Similarly, Cheryl said:

I would say faithfully, I haven't received women centred care. Not delivered by women or women's health centres...so I think, recently I haven't received that kind of care. Um, always with the women's health centre, always a responsibility for my health rested more heavily on me, their expectation was that I would follow through.

Both Julie and Cheryl noted that their facilities were not women centred. For Julie, the criticism was related to the lack of services available. For Cheryl, the criticism seemed to be more about the centre's approach to working with patients; it appeared that "women centred care" and "taking personal responsibility" were not congruent. She wanted her providers at the health centre to have more responsibility if her services were to be seen



as women centred. This desire in particular appears to be in opposition of the women centred values as proposed by Hills and Mullet (2002; 2005); in their definition, women must be respected for their knowledge of their own bodies and be included in decision making. However, Cheryl's perspective is important because it suggests that health care providers could go too far in giving power to patients. Further research is needed to understand this belief more fully.

Again, I needed to be careful with how I understood and used this particular theme. Just because the women could articulate to me that their centres were not "women centred" did not mean that this was a weakness borne out of their own experiences and perceptions. This theme largely arose out of my asking if the centre was women centred or not. As such, I cannot really connect this perceived weakness back to whether or not the women stayed at the facility, or whether a perceived women centred mandate gave any type of meaning to the women's experiences. Ultimately, the women noted that they had certainly received quality care at a women's health centre, but because these often limited services lacked comprehensiveness, the women would not themselves call the services women centred. For 10 years, service providers have complained about the inability to adequately incorporate gender inclusive policy into services, particularly because the Canadian system can be inflexible, health services lack integration, and there are not enough resources (Hills & Mullett, 2002). My findings seem to suggest that women patients value a women centred philosophy to the point that it is a weakness if this approach is not employed.

Lastly, the women had criticisms related to the centres not generating awareness of their services, or not being accessible. Patty, who had not accessed the women's health



centre for more than a year herself, talked about how a younger female acquaintance had come to her for help with a pregnancy, not knowing that the centre existed. The following exchange highlights some of Patty's criticisms about the lack of awareness surrounding the centre's existence:

P: I did have the chance to access the women's health centre for a different reason altogether. I am mentoring a teenage girl who for obvious reasons can't go to her parents about certain things, and she came to me one day saying, "I think I'm pregnant." She wasn't sure. It was sort of a strange situation. And I said, "Well, let's go to the women's health centre; that's what they're for." It took some armpulling, but when I got her there she was very relieved to know that that service was available. She had no idea, and here she is, she's an 18, 19 year old and she had no idea that service was available to her.

B: I'm so glad she had you there.

P: Yeah, yeah. So I guess that's a plus and a minus in a way. Because they're not as securely getting the word out to all the girls that could take advantage of their service, from that standpoint.

In Patty's estimation, the centre was not generating enough awareness of their services. The lack of knowledge about their women's health centre was a concern that several other women also noted. For example, Sarah had a related criticism for her women's health centre. She spoke of issues related to accessibility and knowledge of her facility this way:

Well, it's accessible to me in a university setting, with me with access to the internet and people trying to let me know about services. I would have no idea



how accessible they were for other women. Like, people are always surprised when they come into Planned Parenthood, that we actually exist, or that we offer these services and they actually are free. So I think in general no, but for me, because of my life of privilege, I was better able to know about how to find out about these places, about these things. Like, you have to have access to the internet really, like if you want to find the community health centre nearest you, you have to go online or something.

Sarah recognized that she could not really speak to another woman's experiences with the health care system because her understanding was biased by her own privilege. However, she did suspect that there was little awareness of the women's health centre, and other community health centres, unless you were able to get online.

In the previous chapter, I briefly addressed this notion in terms of whether or not women's health centres were adequately reaching out to women who lacked health literacy. I suggested that women's health centres in Ontario were not generating enough awareness among different types of women, and instead that women with high health literacy (which likely includes women who are educated and of the middle class) were potentially overrepresented in the women accessing these services. Unfortunately, very little research exists on this topic. More than a decade ago, research in Australia addressed the very notion that only "worried well feminist extremists" were accessing services from women's health centres (Broom, 1998, p. 275). What Broom found was surprising; contrary to the popular belief that women's health centres were serving an elite few, the women accessing services at women's health centres were actually more disadvantaged than patients at other community health centres. Again, however, this



research was conducted in Australia, and the health centres were community based rather than hospital based. This may be an important difference. On the other hand, in a case study of one women's health centre in New York City, researchers found that women who accessed services tended to be well educated, employed, and insured, noting that this group of women was not representative of women across the city (Giardina, Cassetta, Weiss, Stein, & Press, 2006). Further research is needed to determine the types of women who attend women's health centres in Canada, and why they do so.

Patty also had criticisms about the general accessibility of her women's health centre. In Patty's city, there were two women's health centres: a community-based one that she preferred, and a hospital-based one. When funding cuts were made, the services provided in both locations were amalgamated into the hospital location, and the community centre closed. In the following exchange, Patty discusses what happened when her preferred facility closed and she was left with no services at all (not even from the women's health centre that remained in her city).

P: I don't really know how the scenario went, but I had to get a referral [to the hospital] in order to get back in to get pap smears done.

B: Are you serious?

P: I'm serious! So my nurse practitioner sent them a letter referring me, but of course because they moved the letter was likely misplaced, and she's in the process of doing another one up for me. I don't really know what the story is on that. As far as I'm concerned, I should be able to just walk in off the street.B: How frustrating. I'm just so blown away that you needed a referral for the same facility that you were already accessing.



P: I was surprised too! I thought, "You know, okay, whatever, okay I've got to do this." I've jumped through hoops before when it comes to government services, so it was par for the course, but yeah - it's like, why?

This lack of accessibility was an issue reiterated by several of the women. In some instances, lack of accessibility was related to the physical location of the facility in relation to where the women lived. However, it remained a widespread concern. Based on this passage, it seems clear that Patty was willing to put in the effort to eventually attend the women's health centre. By giving you this small piece of her narrative, it would appear that she was continuing to fight for her services. However, the reality is not quite so encouraging; in the end, Patty dealt with her problems by simply going without a pap smear for more than the year that is recommended for best care practices.

Ultimately, previous research has revealed that women do suffer from barriers to the health care system. Poverty and lack of child care or transportation have been identified as significant challenges that some women may have to overcome (Broom, 1998; Hills & Mullett, 2002). In this case, it seemed like "bureaucracy" was also a culprit; for women to be required to get a referral and essentially denied care just because their facility had changed locations seems ludicrous by any standard. This particular barrier to access has not been adequately addressed in the literature but has important implications; in this case, it had a significant impact on whether the women continued to access services from a women's health centre. In this case, they did not.

Thus far in this chapter, I have related what the women thought about their women's health centres with regard to perceived strengths and weaknesses. It was clear that the centres were highly valued by the women. This finding is consistent with



previous research indicating that women value women's health clinics and womenfriendly care, and that these modes of care are often preferred to "regular" services (Peters, 2010). However, my research also corroborates previous findings suggesting that women's health centres struggle to meet women's needs beyond reproductive health or other very specific health issues (e.g., a breast cancer clinic; Lundy & Mason, 1994). Unfortunately, this research is 20 years old. A greater effort must be made to evaluate the services rendered at women's health centres and clinics from the patients' perspectives.

### **Role of Connectivity**

Although the women's perceptions of strengths and weaknesses were certainly important for describing their experiences at women's health centres, another important theme seemed to emerge across the interviews. The women talked about the role of connectivity in their health care services, a theme that could not really be seen as a strength or a weakness. Here, I will relate the women's experiences of a sense of community, the role of advocacy, and the need for involvement.

Sense of community. Only one woman articulated that she had experienced a sense of community at their women's health centre. The sense of community she felt was not the result of any direct effort on the part of the centre itself, but instead the other women at the centre. Laura said:

I was at the women's centre and that was kind of therapy because I found a caring community there with another single mom who had a background in a form of teaching, had a background in personal support work. Plus the staff there were terrific. So that was really – I don't think I needed that, I mean, I did see a



psychiatrist too, but um - I think what built it up to help is that we helped each other.

While there was no inherent sense of community to the women's health centre itself, it appeared that Laura had found another like-minded person with a similar background to connect with. By forming her own "community," which she attributed to finding through the women's health centre, her own health had improved. Again, a story of this nature did not appear in any of the other women's interviews. The implications, however, are still significant; they point to the ability to connect with other women as potentially important to the healing process, and to the potential for women's health centres to help this process along.

Previous research has also examined the importance of a sense of community in relation to health, finding that patients with a better sense of community were less likely to experience problems related to choice, cost, and satisfaction with health care services, and more likely to report higher self-perceived health (Ahern, Hendryx, & Siddharthan, 1996; Hystad & Carpiano, 2012; Ross, 2002). However, the sense of community addressed in these examples was not in relation to a particular health centre, but rather in terms of a larger community (e.g., their city or neighbourhood). My findings suggest that this sense of community was also a valuable aspect of belonging to a women's health centre, an area that has not been explored much in the literature. Hunt (1998) did present a case study of a women's mental health centre in Australia using a feminist "woman-to-woman" paradigm of care. This approach can be understood as simply as "being there" for another woman, but generally involves making any space, time, and lay support is



not meant to replace professional care, but rather to augment these services through empowerment; for example, a woman could simply come in and share coffee with other women accessing mental health services to work through issues on her own time. The approach is also often successfully used in the context of births and deliveries, with women benefitting from the presence of a lay woman (Pascali-Bonaro & Kroeger, 2004). Although this woman-to-woman approach is not identical to the experience described in my research, the basic principle is similar; the women were supporting each other in a way that was not necessarily tied to the services of the women's health centre, but would not have happened without it. Future research will need to explore the concept of whether women feel any type of affiliation with other women at their health facilities to truly understand this contribution to the literature.

**Role of advocacy.** I have noted that the women often faced the challenges they experienced in the process of accessing health care by being resilient and seeking alternatives; they made the effort to get to a women's health centre. For many of the women, however, there was something more important than just making an effort to go to a women's health centre. Instead, there was a need for advocacy. In relation to health care, advocacy has been defined as "taking a position on an issue, and initiating actions in a deliberate attempt to influence private and public policy choices" (Labonte, 1994, p. 263). In the health sector, advocacy can be applied in many ways. For example, in a community health setting, advocacy for health issues is taken on by a "community," however that particular community may be defined (Loue, 2006). In this sample, the women described the need for advocacy for both the self and other women. Cheryl expanded on this idea, saying:



But um, I don't think I got [women centred care]. I think that there is a little more now because women are starting to say – I mean, maybe they are a little bit more educated, they are certainly more educated about their bodies. I had some experience before my girls were born so they had, they grew up with that. And that's how I think some of our daughters have grown up with the expectation that they have the right to ask for certain things, they have the responsibility to look into things themselves, to advocate for alternatives and look into that for me, just because they have had issues that they've seen.

Cheryl seemed to be saying that it was more than just making the effort to get to a women's health centre; women needed to ask important questions and demand alternatives. They needed to be advocates for themselves. Self-advocacy has been implicated in the promotion of self-health, but also in women promoting the health of their families (Shieh & Halstead, 2009). It is also highly correlated with health literacy (Shieh & Halstead, 2009), making it an important variable in terms of care seeking behaviours. That is, women must often engage in self-advocacy to get what they need out of their health services; my findings support this notion. However, I am more interested in the women's belief that they needed to advocate for each other (i.e., how advocacy connected them to other women as a community).

Julie also talked about advocacy being an important part of her experience with the women's health centre. As noted in her vignette, Julie ran a women's group. In speaking of her work with this group, she said:

We do a lot of – well why and how we formed is that we – it was just a group of us who were really frustrated with the services, or lack thereof, in the community



and found that it was really brief, and then you're at your service's end and okay, now what? So we kind of developed this group, or created this group, that kind of bridged the gap and is an ongoing group that won't end and you can – we gather resources. This is a big part of what I do, is gathering resources from the community and putting it all together and what's available and what's out there. But yeah, we do, like, advocacy and so we're really trying to get the word out on how important it is.

For Julie, self-advocacy alone was not sufficient, and instead advocating for all women was an important value. She wanted others to access the women's health centre, and was willing to do the advocacy work to make that happen. She further added:

It just takes one. It doesn't even have to be a service provider or an agency, just that one person who is passionate about uplifting women and getting women to unite their voices, and up until this year it was just one woman who was passionate about this, and it was her life and she just conveyed that she believed in us and that we did have influence, and we could influence change if we came together and did what we need to do. Once you give the floor to women, women will take off with it. They'll run with it.

This passage reveals just how strongly Julie felt that women could create social change with their efforts. Responses like this indicated that the women felt connected to each other and that they could advocate for important changes for each other.

Historically, advocacy has had an important role within the Women's Health Movement, and was crucial in making progress related to health care delivered to women and understanding women's health. Many of these efforts were at the grassroots level; for



example, Our Bodies, Ourselves and the Boston Women's Health Book Collective initially began as a small collective of women interested in knowing more about their health, gaining access to adequate care, and sharing this information with other women (Norsigian, Diskin, Doress-Worters, Pincus, Sanfored et al., 1999). When we think of advocacy efforts in North America today, we often imagine leadership from groups and organizations designed to control legislative activity, such as the Women's Health Contribution Program or Centres of Excellence for Women's Health. Professionalized advocacy efforts like these have been particularly important in terms of the third wave of feminism and its contributions to the Women's Health Movement (Boscoe et al., 2004). However, the women in my study did not really mention this type of advocacy, instead focusing on the need for efforts at the grassroots level. In fact, several of the women were engaged in advocacy efforts themselves. Grassroots advocacy efforts continue to ensure progress for women's health all over the world (e.g., see Hatashita, Hirao, Brykczynski, & Anderson, 2006; Norwood & Zahau, 2011; or Schneider, 2009 for recent examples of international women's grassroots efforts aimed at health). Such efforts are also recognized as a critical aspect of women's health initiatives in Canada (Hankivsky, Reid, Cormier, Varcoe, Clark, et al., 2010). One advantage to grassroots advocacy efforts like these is that they are often initiated with little to no funding, making them less sensitive to budget cuts. My findings indicate that women continue to see grassroots advocacy as crucial to improving women's health and health services, to the point where they largely only discussed these types of efforts instead of professionalized advocacy. This research also suggests that advocacy connected the women to each other in meaningful ways. Future research will need to explore exactly how Canadian women are engaged in these



efforts, and to what extent they believe progress can be made for advocacy at both the grassroots and professionalized levels (the latter of which was not addressed in my research).

Need for involvement. The final role of connectivity in the women's experiences at their women's health centres was related to their desire for involvement in both their personal care decisions, and decisions made at the policy level; they wanted to be part of the team making health decisions. I discussed the need for involvement as a separate theme from advocacy because they seemed to be distinct constructs. In terms of advocacy, the women appeared to be referring to mobilizing resources or initiating action with the hope of creating social change. On the other hand, the need for involvement was characterized by wanting to be listened to when decisions were going to be made. While this did not necessarily mean that the women would take action to create change themselves, it meant that they would have a role in informing change created by others.

Based on the women's stories, it was clear that the availability of women's health services was changing. Funding cuts were being made, and some of the women's health centres had actually disappeared or changed drastically. Many of the women talked about the need to include women's voices, and involve women in the decision making about their health facilities and options. To contextualize this desire and need to be involved, I present some of Jane's thoughts on these cuts:

There was no consultation; they basically just announced that they were closing just because it wasn't financially viable or some such nonsense, and moved the health centre and they combined it with the office in the hospital, which also meant that they let go of their library and resource person, and they let go of their



education person. So you know, they are able to offer really, really limited services now. And this really concerns me greatly because women need help, and we need advice, and particularly when there's such a shortage of doctors, the women's health centre is one of the few places women can go to get advice and get treatment, you know? So it's really seriously bad and although there was a lot of protest locally, you know, the local hospital didn't really care, and did it anyway and didn't listen to us.

Here, Jane did not say outright that she wanted to be involved in her decision making. She alluded to it, however, by complaining about the lack of consultation and the fact that the hospital did not listen to the community of women who had opinions on this issue. Interestingly, Jane had not been back to her women's health centre after the cuts.

Other women spoke of their desire to be involved. Patty said simply, "Nothing happens without my voice being involved in the decision making! I swear." She had spoken previously of the need for advocacy for people with sick children who did not know how to navigate decision making themselves. She was someone who did not necessarily need that advocacy herself, as she made sure her voice was heard. "It's sort of – it's become a part of my life, you know. I consider it fighting on the front lines. I refer to it as a war, so I use war terms."

Patty's notion of the need for involvement was at an individual level rather than policy level that would involve an entire community of women. However, it does highlight that Patty wanted to feel like an important member of the team making health decisions, and that anyone who did not allow this was an opponent she would face in a "battle." At the time of this interview, Patty did not feel that she was part of the health



community, and rather felt that she was at war with "them." The implications of this lack of involvement were important; Patty had not accessed health care in well over a year.

Previous research has noted that women need to be involved in the decision making about their bodies in order to receive adequate services (Donoghue, 1996), and that for health care to be women centred, it must involve women in decision making (Hills & Mullett, 2005). The women I interviewed largely corroborated these findings with their stories of wanting to make personal clinical decisions. However, Cheryl's view must also be considered; she believed that her health services were not women centred because her providers did not take enough control and gave her too much personal responsibility for her care. Further research will need to explore this issue, as this finding highlights the inadequacies of trying to capture "all" women's experiences together.

What my findings also revealed is that women wanted to be involved at a higher systems level. That is, they wanted to be involved when decisions were made at a policy level that could have an impact on their lives and the lives of other women (e.g., when one of the women's health centres was being amalgamated into the hospital). Hankivsky et al. (2010) have reported that women themselves must be understood as important stakeholders when conducting research or creating policy related to women's health. Yet patients continue to have a very limited and passive role in influencing heath care (Coulter & Fitzpatrick, 2000). My findings suggest that women are interested in health policy and would like to be more involved; they felt a connection to the health care offered in their communities, and wanted to be part of the team making decisions. Future research and health policy must address patients' voices in a more effective way to ensure that their services are acceptable to them.



## CHAPTER VI

#### **Results and Discussion: Defining and Navigating Health Services**

Having discussed the women's perceptions of and daily experiences at their women's health centres, I will explore how the women defined *ideal* women's health services and navigated their health services as a result.

### **Defining Ideal Women's Health Services**

One of my explicit research goals had been to explore what meaning the women gave to a women centred mandate as they made health care choices. Based on phase one of this project, I also decided to ask the women about family centred care in this same context; this appeared to be a separate approach taken by Ontario health centres, even if I could only clearly differentiate the approaches from health care literature, and not from directors' beliefs about praxis. Lastly, because patient centred care had been tied to the women centred literature and because this term had connections to the early Women's Health Movement, I asked about this paradigm of care as well. I addressed these approaches separately under the assumption that if they were important enough to differentiate in policy planning and research, there was something about the experience of these approaches that was unique in practice.

While I spent some time analyzing the women's responses to my questions about what these terms meant to them, and whether there was any real difference between their understandings, I came to two important conclusions. First, the women had barely heard or used these terms, making their answers to my questions inherently artificial; how could they expound on their understandings of women/family/patient centred care if they had never even thought about these terms? If I wanted to continue to be critical and reflexive



in my approach to conducting an IPA, I had made a fundamental mistake by overlooking one of Parker's (2005) criticisms; researchers often forget the nature of the answers generated in an interview context. I had begun to make inaccurate inferences about the intentions underneath my participants' words, instead couching their responses within my own judgments and decisions about what was important. In other words, trying to get the women to tell me how important these terms were as separate paradigms of care was a pointless task unless it was meaningful to *them* (and ultimately, it seemed that it was not).

The second important conclusion I came to was that while the women *could* articulate differences between these approaches to care when forced to do so, they did not really believe that any of the approaches were being used in actual practice. This perspective stood in stark contrast to the directors, who did not make any real distinction when defining these terms, but at least believed that they employed the basic principles in a meaningful way. I decided that it did not really matter whether the women were able to use the jargon of researchers, practitioners, or policy makers who study constructs like women centred care and want to differentiate this philosophy from family or patient centred care. The women could articulate what mattered to them at a women's health centre, and whether or not they were getting what they wanted. Even if they did not label this "women centred care," it was this data I really needed to examine.

As such, I have decided not to discuss the women's understandings of women/family/patient centred care as separate terms, other than to say that they could articulate minor differences when asked to reflect on whether these terms actually meant anything to them. Instead, I would like to focus on what the women desired in terms of *ideal women's health services* more generally, especially when these were aspects of care



that they felt they had not received. There were two major categories of ideal elements: what women's health services should include, and what they should not include.

What women's health services should include. Most of the women were able to tell me what they would want their women's health services to offer in an ideal setting. To my interviewees, women's health services should include the following: focusing on issues that women alone would face, respecting women's voices, connecting with other women, offering unique services, and incorporating specific training and philosophies of care. Notably, the first three were discussed by my participants as existing strengths of their current women's health centres. As such, I will not focus on these aspects of the care they desired, and instead relate the women's desires about services, training, and philosophies of care.

Beyond suggesting that women's health centres should offer pain-free services (as I have previously noted was a strength of women's health centres) Patty raised another interesting thought about how she wanted her ideal services to be offered. She said:

Idealistically, it would be nice if we could choose and sort of make – choose from a basket of different opportunities, methods of accessing health care. And develop something tailor-made to the individual, you know? So that you could access health care through the hospital, or through a GP, or through a nurse practitioner, through a clinic. It would be done so we have some choice in how we do it, and not be told, "You've got to go here, here, and here and that's the only thing available to you and tough it out." In an ideal world, it would be nice if we had a few selections we could make, and choose from this basket and that basket, and build our own method of health care and have a real say.



This notion of having a multidisciplinary team and allowing for other health professionals to collaborate on comprehensive care for women has been articulated by Hills and Mullett (2002; 2005) as an essential part of the women centred mandate. Clearly, Patty felt that this was not currently being offered by her women's health centre (or any other centre for that matter). Recently, a new model of care called a patient centred medical home (Rosser et al., 2010) has been implemented across Canada and the U.S. Under this approach, a medical practice would include several physicians on a multidisciplinary team (potentially including dentists, nurses, counsellors, etc.) providing a "basket" of health services during flexible hours. Rosser and colleagues (2010) suggest that not only do physicians benefit financially from this model, but patients benefit from coordination of care. It seems that the women in my sample would have appreciated this approach to their women's health services as well.

The women also noted that the training given to providers and the entire philosophy of care behind women's health services should also differ from other types of health services. This included holistic approaches to health, trauma-informed training and approaches, and a pro-choice philosophy. For example, Julie said:

I would hope that if it was women-centred it would be more – using more traumainformed practices, and a whole, instead of just physical health, it would take more of a, you know, emotional, mental, all of that approach. That's what I would see as being a women centred clinic. I think that you would need, or I would want to see, extra training with the staff that are at a women centred clinic, like with being trauma-informed, and being trained to recognize abuse and underlying issues that you may be seeing just the tip of the iceberg, but really being trained to



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see whether there's mental health, or addiction, abuse. More all-encompassing I guess.

Research has previously shown that the training curriculum in women's health at medical schools should incorporate attention to specific issues that women value, such as interpersonal communication and professionalism (Houle et al., 2007). My research also indicates that women believe providers should be trained with specific philosophical approaches in mind, including trauma informed and pro-choice practices. The notion of trauma-informed services can be applied to women's health in many ways, but is often used in the literature related to women with addictions (e.g., Covington, 2008), interventions for battered women (e.g., Domino, Morrissey, Chung, & Nadlicki, 2006), and rehabilitation for incarcerated women (e.g., Harner & Burgess, 2011). For services to be trauma-informed, providers must acknowledge that women are likely to have suffered violence and other forms of abuse in their lives (Covington, 2008). However, other literature also indicates that unrecognized traumas of this nature will play a role in women's general physical and mental health (Felitti, Anda, Nordenberg, Williamson, Spitz, et al., 1998; Messina & Grella, 2006).

Although the inclusion of a trauma informed philosophy has not explicitly been described in the literature related to women centred care, it may once again be implied. For example, Hills and Mullett (2005) advocate for understanding a multitude of factors that affect women's health, such as social, economic, societal, and environmental factors; the experience of trauma would certainly fall under this range of health determinants. My research suggests that some women acknowledge the threat of violence and abuse that



women face, and would appreciate if their providers were equipped to incorporate this knowledge in their provision of care.

Reiterating this notion that the philosophy of care would need to be different, Sarah also said:

Women centred health care would be pro-choice, meaning that the service providers are well-informed that there are reproductive rights, but also supportive of women's right to choose whatever path of treatment that they deem appropriate

for them. Or what else would be inclusive of people's trans identity as well.

Sarah was clear that women should have the right to choose, and was not the only woman who thought transgendered women's rights also had to be taken into account at a women centred facility. This aspect of care has been essential to the Women's Health Movement from the first wave of feminism, and has had a crucial role in health care reform for women (Joffe, Weitz, & Stacey, 2004). A pro-choice directive and access to safe abortions have also been identified as services that are "women centred" (Joffe et al., 2004). However, a pro-choice mandate for providers has not been explicitly cited in Canadian definitions of women centred care. My findings suggest that this principle is important to women, and that they want their health services to be offered under this paradigm of care. Ultimately, the findings lend support for reproductive rights in an era where women's rights to safe abortions are being questioned again (e.g., with Motion 312 put forth by Stephen Woodsworth of the Conservative Party of Canada, and American Republican nominee Todd Akin's remarks about "legitimate rape" and access to safe and legal abortions).



What women's health services should not include. While the women articulated what their ideal services should look like, they also articulated what their services should not look like. The women's perceptions exposed weaknesses in the theory behind offering women's health services in the context of family medicine, and also revealed that they felt deceived by health policy language. For example, when asked about what she thought about women's health services being offered under a paradigm of family centred care, Jane said, "It would be much more complex than dealing with a woman's issue. I don't really quite know why we would want to talk about women's health that way." Similarly, Cheryl said:

It leaves out half of the women! Half of the women aren't in family centred because I know who our government is! The federal government thinks of a family as a male and a female and a couple of kids, and that's not necessarily what family is. So the very fact that family has a connotation in most people's minds, it can be weird still. I think that people will fall through the cracks and people won't be seen as whole people again. A woman who lives on her own won't fit into the model they are looking at. She won't be, she won't be – her relationship won't have the same weight as a male and a female in a marriage... So I guess things are very different and I would not want to see women's centres disappear in lieu of family centres. I think there is a need for both of them.

These passages are indicative of most of the women's beliefs regarding how women's health services should be offered in an ideal world. In the most basic sense, they articulated that a focus on family would be detrimental to women's health care. One



concern was that family centred care implied that a woman had to be heterosexual to attend, and so this model could be perceived as exclusionary.

Much of the literature regarding family centred care supports the notion that this model focuses on the needs of children patients as opposed to women (e.g., Abraham & Moretz, 2012; Johnson, Abraham, Conway, Simmons, Edgman-Levitan, et al. 2008). These women believed that women's health centres should not focus on families at the expense of focusing on women. They also believed that women's health services should be inclusive of all women's needs, not just heterosexual women with husbands and children. This critique of family centred approaches is aligned with research findings suggesting that LGBT people may not disclose their sexuality to health care providers (Chapman, Zappia, & Shields, 2012; Rondahl, 2009), particularly if provider attitudes create an environment where LGBT families do not feel safe (Neville & Henrickson, 2006).

Beyond articulating that taking a family approach to women's health care was not ideal, the women also mentioned one last aspect of women centred care that should not be included in their women's health services. Namely, they described frustration that their health services were labelled as a specific philosophy of care by policy makers and providers, yet often had no substance to back it up. Jane said:

J: I think it is a politically correct term that they just bandy around and it means absolutely nothing to them. I don't really know because I just hear the term kind of bandied about but people don't ever really seem to explain it.

B: Seems more political than anything else.



J: I think so. I think it just sort of sounds good and nobody ever really delivers. If what I described is what they mean by it, then on the whole it's not really happening.

In other words, women did not want their services described one way, and then never see physical results; they saw this as a form of deception. To date, very little attention has been paid to patients' definitions of terms such as women centred or patient centred care. A decade ago, Little (2001) suggested that we do not even know if the principles associated with patient centred care are valued by patients. Unfortunately, we know even less about the value of women centred care. Most research regarding separate philosophies of care has focused on health outcomes, such as how employing these approaches change costs to the system, objective ratings of health, and patient knowledge of disease (Bergeson & Dean, 2006). It is already implied that a term like patient centred care matters (because patient health outcomes seem to improve), so the step to evaluate patient preferences for aspects of this care are forgotten. What my research indicates is that patient perspectives are critical to signify investment in and value for the decisions made by policy makers and providers. These women felt deceived by terms like women centred and patient centred care because they were largely not seeing their own ideals put into practice. They would have preferred to see results than to have the same care "dressed up" as something else. In other words, while these women valued women's health centres and in an ideal world would like to see a unique philosophy of care put in place, they did not really believe it had happened. This may suggest that the experienced praxis does not really reflect conceptual definitions: a problem for researchers, providers, and policy makers to address with greater attention and care.



# **Navigating Health Services**

At this point, I have articulated how women came to access care at a women's health centre, what they experienced when they were there, and what they would have wanted to experience in an ideal world. One last theme I encountered in my interviews was how the women navigated their health services more generally as a result of these experiences and perceptions. In the conceptualization of this project, I had not considered two very important questions; first, what if the women had stopped using their women's health centre, and second what if the women were using other primary health care services in addition to their women's health centre? I realized that the ways women navigated their health care services were much more complicated than I had anticipated. In order to address the complexities of this navigation more fully, I will discuss two major outcomes: withdrawing from care and fractured care.

Withdrawing from care. Although it was clear that the women valued their health and what women's health centres had to offer, many of the women had stopped attending their women's health centre or withdrew from certain health care services entirely. In particular, the four older women in my sample were not using their women's health centre at the time of my interviews. Interestingly, these four women lived in locations where only a hospital based women's health centre was available.

The reasons why women stopped attending their women's health centre varied. Jane had largely stopped attending because budget cuts had resulted in a loss of the services she accessed at the women's health centre, and because the centre was now housed at the hospital. She said:



No, I actually haven't even been there, really. You know, I have to drive down there, and I have to pay \$6 to park. I have to search around the hospital to find where they are to find out they can't do anything for me. I haven't even been there yet. It's just a real kind of tragedy. I suppose I would say that if I needed specific information, I think I would go and see if I could find stuff in their library. And I think I will kind of keep tabs, just in case their situation does improve and they actually can do more than they're doing at the moment. I think the thing about the hospital too is that they come up with all sorts of recipes that look so good like a little while ago they had a room in the hospital where you could go and you could write in a suggestion box a kind of thing how you think the hospital should be run. And it was there for about two weeks and then it vanished and when I tried to track down what happened to it, the woman said, "Oh, it was wonderful, and we got so much useful information!" What, in two weeks?! And where do I go if I want to give you any information? "Well, we've got all the information we need." Oh, okay. And that's kind of how we as patients are treated. So it's really difficult to let them know how you feel, and even if you do let them know, they really don't listen anyway. So yeah, the women's health care centre is supposed to be an alternative, but that's not really adequate as it is.

Jane had noted in her interview that she preferred her services at the women's health centre to the care provided by her general practitioner, and that she valued women's health centres in general. The funding cuts and new location, however, influenced her decision to not continue accessing services. Although her understanding of the hospital facility's services was based largely on her perceptions and expectations (i.e., because



she had not been to that particular unit yet), her previous experiences with the hospital in general had influenced her behaviours.

Patty had been attending a community based centre, but it had been amalgamated into the hospital location; when her initial referral to attend the hospital had not materialized she did not follow up. Conversely, Laura had not liked the nurse practitioner who had replaced the first one she had dealt with, and stopped going. Cheryl, meanwhile, could only access reproductive health services, disliked the distance of the hospital from her home, and also decided to no longer attend. However, unlike Jane, who had a general practitioner to fall back on, these three women did not have a general practitioner; in most cases, they simply went without services.

In order to address the magnitude of this decision, it is important to contextualize the women's experiences. For example, Patty said, "I also haven't had a pap in over a year." That Patty had gone without a physical in the time since her women's health centre had closed was perhaps unsurprising; she had found pap smears given by her general practitioner very painful. However, Patty also had not had a general practitioner in "a few years." Based on her health history, and that of her daughter, she had "fought the good fight" with health care providers for years. Unfortunately, she had come to a point where she was simply burned out by the perceived effort required.

Similarly, Laura said, "No, I haven't been to a GP in 10 years. But I have a therapist now. But I don't think it's working with her." Laura had not had a physical in more than two years, but had accessed mental health services regularly. As I have already mentioned, however, Laura felt that these services lacked continuity, and largely felt marginalized by the system. She said:



Um, well, I'm on the waiting list but it's been 10 years, I can't believe that. I would never believe that you would tell me 30 years ago or 20 years ago that I wouldn't have a doctor. Because that meant at the time, you know, like I would like to have, I would love to have it.

Cheryl, meanwhile, did not have a general practitioner. Since the moment she had decided to not attend her women's health centre anymore, she had been assigned to several doctors, only to have them move away before she could even get an appointment. In the following exchange, Cheryl talked about her decision to not access certain services:

C: I had one doctor – now, they've asked me to see the doctor, and I've said, "No." I won't come in... I can't deal with it. I'd seen five different people.

B: In three years?

C: And I haven't had a chart, but only one doctor would know me if I'd walked in. At the time of the interview, Cheryl was just weeks away from having a radical reconstructive hysterectomy. She had clearly accessed some health services, but did not want to deal with a system that could not provide her with the continuity she needed, so withdrew from standard doctor visits.

The reasons for not accessing women's health centres (or other important services) appeared to be related to lack of initiative, the barriers associated with attending, and the women not liking a particular provider at their women's health centre. It was evident that the experience of marginalization had played an important role in their behaviours. Again, in the health care setting, marginalization has been found to contribute to feelings of isolation, having limited options and power, and the feeling of being silenced (Leipert & Reutter, 2005). It seems that the experiences of these women corroborate these findings



only too well; they had withdrawn from services even though this behaviour was not aligned with best practices for women's health.

I would like to focus on the first two reasons (i.e., lack of initiative and barriers) in particular as they were directly tied to changes that many of my participants experienced in the infrastructure of their available services (e.g., funding cuts resulting in their community centre closing). I believe that these first two reasons for not attending a women's health centre are also highly related to the second major way that the group of women who were not accessing women's services differed from the women who were (i.e., the former only had a hospital location available for their women's health centre). To clarify, the women who seemed to lack initiative in attending their women's facilities or experienced barriers in accessing new women's services (e.g., needing a referral), were largely placed into that situation because their community based facility had closed or was amalgamated into the city's hospital unit. Again, feelings of marginalization seem to be implicated here. However, to me this also indicates that cutting women's services was detrimental to the women's health care utilization. It also seems to indicate that the women preferred community based women's health centres over hospital based women's health centres to the point where they would have rather gone without services than attend the hospital.

Trying to explain this preference for a community based centre by deferring to previous literature is difficult; research comparing community based clinics and hospital care have shown that patient satisfaction and quality of care are largely comparable between the two (Liu, Chapko, Bryson, Burgess, Fortney et al., 2010). With regard to objective measures of quality and cost to the system, evidence has shown that in fact



community centres may not be as strong as hospitals (Sibbald, McDonald, & Roland, 2007). Yet, we also know that women tend to prefer the care at women's health centres to other models of care, especially for their routine health screening (Peters, 2010). Peters showed that for women-specific health screening tests in particular (e.g., mammography and pap tests), women want a woman-friendly and safe environment that can offer continuity of care; this appeared to be the case for my interviewees as well.

It also seemed that the women in my sample had preconceptions about the type of care a hospital could provide, instead preferring a community based women's health centre that felt more holistic and "women friendly" in its approach. Preconceptions of health care treatment have been implicated in explaining why patients delay or avoid health care later (Moore, 1995). Ironically, these preconceptions may be inaccurate; again, research has indicated that community centres do offer improved access, but the quality of care can suffer and direct financial costs can actually increase (Sibbald et al., 2007). Further research is necessary to determine the quality of care and continuity of services available at different types of women's health centres (i.e., community and hospital facilities) in order to determine the reasons why women may show preference for certain services.

There may be other reasons that the women did not attend. For example, while these women did have various ailments and medical issues they were suffering from, all of the women seemed to be relatively high functioning. This is an important point; research has indicated that presence and type of symptom are important factors in determining health care utilization (Lauver, 1992). In other words, regardless of whether the women valued their health and women's health centres, if the impetus to attend was



not strong (i.e., there was no real health concern) they simply may not have gone. Previous research with lesbian women specifically has also shown that the more comfortable women are with their provider, the more likely they are to seek preventive care (Bergeron & Senn, 2003). This may also be a potential reason for not attending a hospital facility; the women clearly showed comfort with community centres as opposed to hospital centres. Overall, however, I believe that cuts made to their facilities, which resulted in large changes to the infrastructure and delivery of their services, may have simply been "the last straw" in a series of marginalizing experiences. In this case, these experiences may have been enough for the women to go without primary care.

**Fractured care.** I have already conveyed that none of the older women were currently using a women's health centre. However, the pattern among younger women was seemingly the opposite of going without care. Instead, the younger women were not only accessing care from a women's health centre, but sometimes multiple women's health centres or other clinics, and a general practitioner. In other words, they were receiving fractured and uncoordinated care from multiple places. The reasons for this trend included: needing to access care at multiple places because one or more other locations could not meet their full needs, and not trusting their general practitioner.

In Julie's case, a recent move meant that her general practitioner lived six hours away. She could not find a doctor in her current city, and accessed the women's health centre nearest her to supplement her services. She said,

And I don't want to leave my doctor because he's pretty good and I never know who I'm going to get, or if they're even going to stay in this area. So, it's kind of risky to do that, to leave the doctor and try and get a new one or whatever.



To get by, Julie had accessed the women's health centre for herself and emergency services for her children when she was really in need of health care.

Sarah, meanwhile, currently had a general practitioner in her city. As I have already conveyed, however, she was extremely dissatisfied with this doctor. While Sarah had initially used the women's health centre because she had lacked OHIP coverage, she continued to use the centre because of her dissatisfaction with her doctor. She said, "I just do not go to her – just because I found better care elsewhere." Most recently, she accessed care from the women's health centre and another community health centre. At one point, she had been using the health services at her university in addition to these two health centres. Sarah's reasons for accessing care at so many different places were complex: she kept her general practitioner for referrals, accessed the women's centre for sexual health and birth control, and attended the community health centre for her needs related to anxiety and depression. At one point, Sarah said, "I actually worked at a community health centre myself so I know how to work the system." She knew she could not get all of her health needs met at one single facility, and instead had to attend multiple places.

Lastly, Helen also accessed care from multiple providers. She travelled back and forth between two locations because she had a short-term contract to work in another city. As a result, she maintained her general practitioner in her hometown, but also attended a women's health centre in both cities, and sometimes accessed services from the university she attended. In the following exchange, Helen discussed the potential implications of seeing so many caregivers:



H: Sometimes I wonder if I'm doing the right thing by going all over the place but ultimately I wanted a female doctor.

B: Did you feel like the continuity of your care changed at all, you know, from accessing multiple places? Or did you feel that people knew you there?

H: Um, in terms of continuity there was a lot of re-explaining of history and things of that nature but I came to expect that.

Helen felt uncomfortable talking with her male general practitioner about "femaleoriented" issues, and also felt that he could not understand her "aesthetic" concerns. At the same time, in the following exchange she spoke of why she kept going to back to see him:

H: Yeah and I've never actually – with my GP that I have, who I've had since I was born, so – I've never actually gone through the process of [finding someone new]

B: So that's nice, too. Having someone who has known you for that many years.H: Yup, yeah. Which is why I've always gone back to him for more general things. Any time I need a prescription refill or something.

Clearly, Helen also perceived that she could not manage all of her needs at one facility. She kept her general practitioner for general refills, attended one women's centre out of necessity (i.e., travelling), and the other women's centre for what she perceived as women-related issues. I did not ask about why she accessed her university's services.

I termed this section "fractured care" because many of the women had noted they preferred greater continuity of care and for their providers to "know" them better. The women also often stated that this practice of having to attend health services in multiple



places was not ideal. However, the women had to persevere through the weaknesses of the system to get what they needed out of their services. Research on women's health from the U.S. indicates that it is extremely common for women to have multiple providers (Ranji & Salganicoff, 2011). While this may help women manage their many needs, the ability to provide continuity and coordination of services is questionable (Ranji & Salganicoff, 2011). In contrast to what has been found in the U.S., however, it was the younger women rather than the older women who seemed to be accessing multiple providers. Unfortunately, in the latest Statistics Canada report on women and health (Turcotte, 2011), there is no discussion on the patterns of multiple provider usage among women. My findings point to a need for further research in this area to determine if this is a pattern that many Canadian women are engaging in.

The reasons for the women seeking care in multiple places included a perceived necessity and mistrust of their general practitioner. In the case of the former, this finding indicates that women's health services may not be offering comprehensive enough services. That is, the women had to attend other facilities because they could not access all of their services in one place (even though they wanted to). I have already discussed this criticism in relation to women's health centres and noted that this concern has held for nearly 20 years (Lundy & Mason, 1994). These findings thus point to a need for women's health centres to do a better job at providing comprehensive services. Another perceived necessity for accessing care in multiple places was that the women needed to use their women's health centres when their general practitioners were not available (e.g., when a woman lived in a different city from her doctor). Again, the percentage of



Canadians without a regular doctor has increased steadily in recent years (Turcotte, 2011), so this finding may not be surprising.

Because of the realities of Ontario's health services, these women showed resilience and creativity in cobbling together a group of health care providers from which they could gain the services they need. This finding suggests that the Canadian health care system must do more to ensure its residents have access to the facilities they need, particularly if continuity of care is a goal. This may also indicate that the younger women were particularly savvy about their health services. I had mentioned that ideally, the women may have liked a "one-stop shop" where they could pick and choose what types of services were available in one physical location. I suggested that the "patient centred medical home" (Rosser et al., 2010) was a model that could address this desire. When this was not available to the women, however, it appeared they may have tried to make this happen by attending the different providers they needed. Unfortunately, these efforts were not coordinated by the providers themselves, which led to the women feeling that the continuity of their services suffered. My research has revealed an important place to conduct research related to women's access to health services; namely, there is a need to examine where women are receiving the bulk of their services, and how we can better coordinate these efforts.

In terms of the latter factor (i.e., mistrust of previous providers), this finding also revealed something more about the context within which the women were pushed to a women's health centre in the first place. As I detailed in Chapter IV, mistrust has been implicated as an important factor in determining utilization of health services (Pearson & Raeke, 2000), and my findings certainly corroborate this finding. Additionally, there has



been a call to explore how mistrust specifically impacts this process (LaVeist et al., 2009), and my findings begin to fill this gap. Namely, the younger women did not just give up their previous services as a result of mistrust, but now accessed care from their general practitioner *and* a women's health centre (and sometimes, another facility as well). The mistrust they felt in their provider was enough to push them to a women's health centre, but not enough to make them abandon their provider entirely (potentially because they recognized a shortage of doctors was upon them). This finding has important implications for Canada; coordination of services and continuity of care have been implicated in reducing costs to patients and the system, and improving patient outcomes (e.g., Brown, Bornstein & Wilcox, 2012; Grant & Greene, 2012). Unfortunately, providing coordination and continuity of care is challenging when multiple providers are being accessed by patients (Ranji & Salganicoff, 2011). It is thus essential to conduct research on where women are accessing services to determine the impact at the individual and system levels.

In general, these patterns in women's care seeking behaviours (i.e., going without services or seeking services in multiple places) can be couched within current models of health behaviour, such as the Health Belief Model (Rosenstock, 1990) or the revised Behavioral Model of Health Services Use (Andersen, 1995; Andersen, 2008). For the latter in particular, which considers the contributions of the environment (e.g., health care system), population characteristics (e.g., enabling resources), specific health behaviors (e.g., using health services), and health outcomes (e.g., satisfaction), the experiences of the women here seem to corroborate theory. Again, my research was merely exploratory, and does not provide enough depth to truly apply these models to explain their



behaviours. Future research will be needed to see if other Canadian women are engaging in these patterns. Once it has been determined that this is an area of concern for the Canadian health care system, we can begin to apply theory from the literature on utilization of health services to explain these behaviours.



### CHAPTER VII

### **Results and Discussion: Understanding and Contributions of "the Self"**

In this final results/discussion chapter, I will use an intersectional lens to explore how certain aspects of the women's identities contributed to their experiences with women's health centres. Thus far, I have tried to include such an analysis and discussion within the past four chapters in two ways. First, in Chapter III, I provided vignettes of the women's experiences. I tried to personalize their stories so that their individual experiences were not "lost" to the larger themes of the IPA. Certainly, these vignettes offered the most detail in a single place about how each woman self-identified. Second, peppered throughout Chapters IV, V, and VI, I have alluded to "identity" factors playing significant roles in shaping the women's values, perceptions, understandings, and experiences with their health care (e.g., age). In the remainder of this chapter, I will summarize these factors. Ultimately, this involves a discussion of how the women selfidentified, or at least how they recounted aspects of their identity to me (and how I perceived them).

## **Role of Self-Identity**

In this section I will address the aspects of the women's identities that seemed to have the most salience to their women's health care narratives. This involves a discussion of the characteristics that united their experiences, the characteristics that differentiated their experiences, and other important factors that I could not fully address based on my line of questioning (but still deserve attention).

**Uniting women's experiences.** I have described a variety of "experiences" at this point, such as those prior to attending a women's health centre, those while at the



women's health centre, and others related to navigating health care services more generally. For these first two in particular, the factors that made the women in my study similar played an important role in giving their stories some unity.

One of the first ways the women were similar was, of course, their gender. I have spent some time "unpacking" the women's desires to receive services that focused on women in particular, and also the importance that women's services not be lost to family services. It was clear that the experience of gender was salient to their health care needs. However, there was very little discussion from my participants about feeling marginalized because of gender, and other factors that affected their experiences were generally mentioned more frequently. I believe this lends credence to the need for an intersectional analysis.

As I have noted in other chapters, the ways that these women were similar to one another included class and/or education, health literacy, health status, and location. It is also important to note that even though women face a "gender disadvantage" in relation to vulnerability to poor health and access to health services (Sen & Iyer, 2012) other aspects of their identities largely indicated institutional privilege; as such, these women's stories represent the interests and experiences of a very specific intersection of women. The inability to generalize beyond this group of women, or those with similar advantages, is a limitation that must be acknowledged.

Unintentionally, I recruited a particular sample of women who were well educated and/or of the middle class (which would likely implicate education as part of this experience). I combine education and class together because I simply did not do a good enough job of extrapolating specific details from the women about their lives. It is true



that at least two of the women were concerned about their finances (i.e., Jane and Laura), but no one was currently living in poverty. Most of the women talked about having a Bachelor's and even a Master's degree, including Sarah, Laura, Cheryl, and Helen. While Jane, Patty, and Julie did not discuss their formal education, based on their self-reported middle class status, how articulate they were, and their health literacy and specific knowledge of the health care system (e.g., Julie using the term "trauma-informed"), I was very confident that the women had at least completed high school. Admittedly, however, this is speculation. Patty also talked about serving on a hospital committee, and Julie ran a women's group that engaged in women's health care advocacy. Jane also discussed her attempts at starting a women's group at her women's health centre, including issues of recruitment. Each of these experiences implies a level of engagement and thinking that seem to verify my belief that they had some formal education.

There may be a big difference in the thinking and experiences of a person who has a Master's degree and one who has a high school diploma; it is well established that health outcomes improve as level of education increases (Schillinger, Barton, Karter, Wang, & Adler, 2006). The "middle class" is also a wide-ranging indicator; being at the very top or very bottom of the class group could certainly change a person's experiences. However, research has largely shown that the largest differences in health outcomes occur at lower incomes (Backlund, Sorlie, & Johnson, 1999). Sen and Iyer (2012) also suggest that analysis of groups in the middle of the social spectrum may not yield the large (and generally statistically significant) differences seen between groups on opposite ends of the spectrum. As such, they advocate for studying "middle groups" experiencing



intersections of different axes of power (such as being a middle class woman) to offer a more nuanced understanding of the effects of these experiences.

In relation to health care seeking behaviour specifically, previous research has indicated that socioeconomic status (SES) is a crucial factor; there are important differences in patterns of access for people with less education and wealth compared to those with greater education and wealth (e.g., Adler & Newman, 2002; Fredericks & Sidani, 2012; Grover, Kumar, & Jindal, 2006). However, evidence is often mixed. In Canada specifically, it has been shown that people with higher SES use primary care less frequently, but are more likely to have access to specialized care (Dunlop, & Coyte, & McIsaac, 2000). This may in fact be one factor that contributed to why so many of the women in my sample were going without primary care services; their SES had afforded them a particular health status that allowed them to prolong seeking services without many negative consequences. Previous research as also indicated that "non-poor" women can draw upon their SES entitlements to modify any gender disadvantage they experience in relation to health care seeking (Sen & Iyer, 2012). That is, they have access to critical resources not available to women experiencing poverty. I believe that the experiences of the women in my sample support this finding; when taken in concert with their health literacy and health status, my interviewees faced barriers associated with health care access by seeking options that other women may not have been able to partake in (e.g., a women's health centre).

As I have mentioned in previous chapters, health literacy is a factor that is tied to education and class (Volandes & Paasche-Orlow, 2007), and also united the women in my sample. Health literacy has been identified as "underexamined" in health research



(Saha, 2006), though has been implicated in health status and health-related behaviours such as care-seeking. Namely, limited health literacy has been shown to have a greater impact on health outcomes and preventive health care use than either education or race (Schillinger et al., 2006; Scott, Gazmarian, Williams, & Baker, 2002; Volandes & Paasche-Orlow, 2007). We would generally expect high health literacy to lead to better health outcomes and care seeking patterns. However, Berkman and colleagues (2004) found that women who had marginal health literacy had a greater chance of never having a pap test than both women with high and low literacy. Because the relationship between health literacy and certain care seeking behaviours is tenuous, more research is necessary. Berkman et al. also found that higher health literacy has consistently been associated with greater understanding of health services, and my research appears to offer support. For example, the younger women were savvy enough to get all of the services they needed from multiple providers, suggesting that they understood what the health care system could offer them.

A third way that the women in my sample were united is in their health status. It is true that the women differed in the types of health issues that most affected them. For example, some suffered from bouts of depression, some had sexual health concerns, a few of the women had trouble sleeping or were physically tired, and there were many other issues they elaborated on throughout their interviews (e.g., being a stroke survivor, having PTSD, asthma, bladder issues, etc.). Earlier in this chapter, I identified specific health concerns as a way that made their stories unique. However, even with these various concerns, the women's general health statuses seemed to allow them all to get through their daily lives with minimal impact on their functioning. None of the women



were house-bound or severely limited. It is true that one woman (Cheryl) was having a hysterectomy; however, she was healthy enough that she would not see the general practitioner they had assigned to her.

I mention this notion of the women having similar health statuses (i.e., adequate at the very minimum) as something to consider when trying to explain the types of choices the women made with regard to their care seeking behaviours. As I have previously noted, presence and types of symptoms are one factor associated with care seeking behaviour (Lauver, 1992). More generally, health status has been identified as an important factor in determining timely access to health care services (Beatty, Hagglund, Neri, Dhont, Clark, et al., 2003). Clearly, the women in my sample could largely afford, health-wise at least, to either go without services or search for alternatives. In this case, I must admit that I have inferred that each woman's health status is minimally "adequate" based on her health behaviours and descriptions of her experiences; in other words, this is my interpretation of their stories. Unfortunately, I did not ask the women to rate their health status more globally, and this shortcoming must be acknowledged when attempting to understand the impact of health status on these women's health care seeking behaviours. Once again, future research will need to explore how health status contributes to care seeking, particularly in the context of choosing care that is an "alternative" to a general practitioner or family physician (as women's health centres were for these women).

Finally, I want to address location as a means of uniting my participants. These women all lived and accessed care in Ontario. While several of the women had initially come from places outside Ontario, and even Canada, their experiences were all framed



from the perspective of accessing services in Ontario. Some research has suggested that although training of health professionals is coordinated and social policies are shared across Canada, there is variation in the provision of care by province (CIHI, 2006); this makes generalizing my findings difficult. As I have already mentioned in the previous chapter, accessibility of health services varies by region of Ontario. However, the issues related to health care access exist across Ontario (Singh et al., 2010), and my participants represented five different LHINs. Because I could not obtain a sample of women from the same facility, this is also a factor that differentiates the women from each other. Ultimately, I was trying to address the experiences of women in Ontario, and have succeeded in this regard.

**Differentiating women's experiences.** I have explained how some basic characteristics connected my participants' experiences, which allowed me to locate some themes across the interviews. In several instances, however, the women's stories differed greatly. Two important issues that differentiated the women's experiences from one another appeared to be age and type of women's health centre accessed. In several places in this chapter, I have noted when age was an important factor to my analysis. Unwittingly, I ended up with a sample of women from two main age groups: 50 to 60 and 20 to 30. This age difference is significant when describing the women's experiences and beliefs about health care. For example, when the women described their personal concerns regarding their health care services, these often differed along lines of age. With regard to the younger women, Sarah's issues were about contraception, Helen's were about acne and appearance, and Julie's were often framed from having very young children to care for. On the other hand, the four older women discussed how aging and



not having services for their age group were problematic, and more than one older woman was concerned about menopause. Another way that this division of age came into play was in how the women navigated their health care systems. The younger women were all currently accessing women's health centres at the time of my interviews, while none of the older women were. It is clear from my interviews that as women aged, their health care needs evolved. These age differences contributed to the perspectives of what each woman needed from her health services, and how she went about addressing those needs.

Age has been identified as an important variable related to health status (Denton et al., 2004) and care seeking behaviour (Stidham Hall, Moreau, & Trussell, 2012). Age also interacts with gender in important ways; for example, middle aged men tend to suffer from chronic disease and thus have higher mortality rates, whereas older women are more likely to suffer from poor health and chronic disease (Denton et al., 2004; Turcotte, 2011). As such, it is critical to conduct research examining the intersections of gender and age in order to fully grasp how these factors shape patients' experiences. Interestingly, recent findings suggest that younger women are more likely than older women to not access reproductive health services (in this case, primary and preventive sexual and reproductive health services, and not child-bearing service use; Stidham Hall et al., 2012). In my research, I found just the opposite. It is thus essential to conduct similar research on a larger scale to determine what patterns exist in health care utilization for Ontario women.

In trying to examine how intersections of different axes of power factor into the utilization of reproductive health services, Stidham Hall and colleagues (2012) found that



younger women showed similar patterns in care seeking to undereducated, underinsured, and immigrant women. Older women, meanwhile, had similar rates to those of higher socioeconomic status. For younger women in particular, after almost a decade (1995 to 2002) of improved rates of reproductive service use (Potter, Trussell, & Moreau, 2009), Stidham Hall et al. (2012) reported decreases in service use over the time period of 2002 to 2008. They suggested that this may have reflected decreases in the number of family planning and public sector clinics serving women, which typically see high numbers of young women. They asserted that socially conservative policies on reproductive health and family planning contributed to inequalities in reproductive health care use (Stidham Hall et al., 2012), a point that may be relevant for my interviewees as well.

I saw exactly the opposite pattern of care in my research; the younger women were accessing care and the older women were not. One factor to consider may be marginalization and other negative experiences with the health care system. It may be that after decades of dissatisfaction and mistrust, the older women felt powerless to "fight" anymore. The younger women simply may not have reached that place yet. However, the older women all lived in locations that did not have a community women's health centre (which I have noted was the preferred modality for treatment). Instead, the older women lived in locations where only a hospital based centre was available. Once again, this speaks to the issue of regional accessibility; future research will have to explore the availability of services before we can make important conclusions about location. Although it may not be that the hospital offered worse care, the women *did* complain about the hospitals. For example, Laura said, "The whole hospital thing interfered." On the other hand, this issue may reflect that funding cuts resulted in the



community centre closure and only the hospital remained as an option. Two of the women (Patty and Jane) discontinued their use of their women's health centre because the services were now offered at the hospital. Cheryl did not provide specific complaints about the hospital, but did complain about access to her facility. Future research will need to explore whether and how the type of facilities available to women affects their health care seeking behaviours.

**Other important factors.** As a final way of addressing the role of the women's identities, I want to mention other categories of difference that I could not fully incorporate into my analysis, including race and culture, sexual orientation and relationship status, and immigration status.

With regard to race and culture, several women self-identified as "white" or "Caucasian." Of the seven women, only one spoke of a race and/or cultural factor; Cheryl discussed reconnecting with her First Nations heritage. Unfortunately I did not ask any specific questions about their race, ethnicity, or culture; I had planned on leaving it up to the women to discuss the most salient aspects of their identity. As such, I cannot fully address this factor as a contributor to the women's experiences. It is possible, however, that this lack of discussion about race and culture indicates that these were not salient issues to the women. Instead it may be that this was not a "problematic" issue, or imply a particular type of privilege where speaking of these issues was not necessary because they do not factor into their experiences; in other words, most of my sample may have been white. This is, again, speculation at best.

With regard to sexual orientation, only one woman identified outright as heterosexual. All the other women were either currently in, or previously had been in, a



heterosexual relationship. Because I did not actually ask the women if they were heterosexual, I cannot include this factor in my analysis. However, the fact that many of the women were in a heterosexual relationship may be important, especially considering the women's beliefs about family centred care, and that fact that they largely considered this form of care heterosexist.

Finally, immigration status was a factor that was discussed by two of my participants, albeit very briefly. Sarah had recently moved to Canada from the U.S. and had undergone a period without OHIP coverage; her experiences with the Ontario health care system were certainly affected by this factor. Similarly, Laura had immigrated to Canada 30 years ago and her experiences with two health care systems would likely have also factored into her understanding of her health care needs. Unfortunately, I did not address these issues in any depth during the interviews, and thus cannot adequately address this factor in my analysis.

As I have noted, my participants represented a particular, largely privileged, intersection of women. The most important implication of this fact is best contextualized within the reality that regardless of their privilege, the women experienced marginalization by the health care system on a regular basis. If these complications exist for a fairly privileged group of women, it is likely that a more marginalized group would experience the negative impact of the health system in a more powerful way. While these women's experiences have thus given some direction on where to place our research focus, future efforts will necessitate a sample of more diverse women.



#### CHAPTER VIII

### Conclusions

Over the last five chapters, I have tried to relate the perceptions of four directors of women's health centres, and seven women's individual stories of their experiences with women's health centres and women centred care. My ultimate goal was to weave a cohesive narrative based on these collective stories. I would like to discuss the implications of this research in terms of the major findings of each chapter and how they relate back to the larger narrative, address important limitations, and then make my final conclusions.

**Chapter III.** In this chapter, I related the results of phase I of this project: a survey of directors' beliefs about the women's health services they oversee. The main finding of this chapter, though preliminary due to the small sample size, was that directors of women's health centres did not define women centred care differently from other forms of care (e.g., patient or family centred). However, they did believe, almost uniformly, that they were putting these women centred principles into practice. While health care literature generally separates these approaches to care, recent work has occasionally combined paradigms, such as referring to "patient and family centred care" as if it was a single approach (Abraham and Moretz, 2012). Yet politically speaking, it has seemed advantageous for separate principles to be defined. For example, one director indicated that her facility had "moved away" from using women centred language, implying there was some benefit to this choice. Ultimately, if the principles are being employed, it should not really matter what they are called; they have been identified as



important by Hills and Mullett (2002; 2005) and others (e.g., Barnett et al., 2001), and an application of them under a different name should be acceptable.

Unfortunately, this belief that women centred principles were, in fact, being employed stood in stark contrast to what the women I interviewed experienced. They believed that there were differences in these approaches *in theory*, but that these principles were often not being put in practice. This rift between what providers (i.e., the directors) perceived about services at women's health centres, and what patients (i.e., the women) perceived about these services leads me to ask a remaining question: if patients do not actually see any benefit from these different mandates, what is the point in defining them?

What these findings may reveal is that even though these constructs are often referred to by providers and policy makers as separate approaches, there may be no real distinction. Similarly, my findings may also indicate that Ontario women's health centres are simply *not* women centred as Hills and Mullett (2005) and others have conceptualized this care. If women's experiences do not align with what is intended by providers and policy makers, we cannot confirm that these theoretical approaches are being employed in practice. Women's health centres *do* matter to women, as I have noted through the last several chapters, but medical jargon does not. Women would simply prefer to get what they want, and in many cases, did not.

Ultimately, the findings of this chapter indicate that women centred care is still a fragmented and poorly understood construct. I alluded to this notion in my introductory chapter, when I attempted to differentiate the construct from other similar ones. If we are to continue to use terms like women centred care in any useful way, they must actually



mean something. Potentially, women centred care might come to only refer to research and policy approaches (i.e., one of the two applications of women centred care I suggested in the introductory chapter), while "women's health centre" might apply to the primary care setting. Based on my literature review and the experiences of my participants, I believe we may be applying the policy/research side of their model very well in this province, but that more effort is necessary to ensure the primary care side of this model. Further research is needed to support these suggestions.

**Chapter IV.** In this chapter, I related the story of how the women came to choose a women's health centre. Specifically, the women experienced weaknesses in their health services, marginalization by the health care system, and lack of services in general to the point that they became dissatisfied and mistrustful of the health care system; in other words, they were ready to seek an alternative. It is this outcome behaviour in particular that has the greatest implications for future research. To date, most of the care seeking behaviours associated with mistrust and dissatisfaction have been negative (e.g., delaying treatment). My findings instead revealed that the women additionally engaged in other *positive* behaviours, like seeking out other options. This finding is supported by previous research showing that women are more likely to change their physician due to dissatisfaction with their care (Bean-Mayberry et al., 2003; Colman, 2003).

Additionally, in framing a women's health centre as an "alternative" to their traditional general practitioner, I can potentially make some connections to previous literature regarding other alternative health care models, such as complementary and alternative medicine (CAM). It is true that women's health centres tend to follow a more traditional model of care than common conceptualizations of CAM, but there are often



important differences in women's health centres from regular services (e.g., inclusion of different types of providers such as nurse practitioners; education on alternative methods for menopause, etc.). Sirois and Purc Stephenson (2008) also found that dissatisfaction was a common motivation for patients to use CAM. However, some research indicates that dissatisfaction and mistrust may *not* be the most important factors that contribute to patients exploring their options like CAM (Astin, 1998; LaCaille & Kuvaas, 2011). This finding must be contextualized, of course; for the most part, people use alternative forms of care to complement rather than replace their services (Barnes & Bloom, 2008). When people largely abandon conventional forms of medical care and rely heavily on alternative care for their primary services, however, patients' dissatisfaction and mistrust with previous care have been found to be strongly implicated in this decision (Astin, 1998). I believe that the women in my study were more similar to this latter group of individuals looking to replace their services, which is why dissatisfaction and mistrust was so important to their decision.

The second half of this chapter was also important; if the women were in an environment where they could gain awareness of a women's health centre, valued their health and what a women's health centre could offer, and were willing to persevere through the challenges in attempting to access a women's facility, they made the meaningful decision to seek a women's health centre. Literature specifically related to patients' traditional provider choices is limited (Fotaki, Rolan, Boyd, McDonald, Scheaff et al., 2008). What we do know is that patients may choose their doctors based on convenience or recommendations from their loved ones (Billinghurst & Whitfield, 1993; Wun, Lam, Lam, Goldberg, Li, et al., 2010). Previous research has also suggested that



part of the decision making process specifically related to choosing a provider largely follows a three-step process: patients decide to seek care, they choose a provider, and then they form expectations about that care (Wolinsky & Steiber, 1982; Wun, et al., 2010). My research seems to suggest that the second step (i.e., the process of choosing a provider) is complex and involves multiple individual and contextual factors that may not have been explored adequately, and may largely be driven by health literacy. Dissatisfaction and mistrust with previous services may also contribute to this process. Additionally, the actual process women undertake in seeking an alternative may be very complex and meaningful to the women. At this point, however, more research is needed to support these ideas.

What this narrative about women's health care choices ultimately indicates is that these women were invested in their health and the provision of their health care services. They made active decisions (even when that meant to not access health services) and wanted to have an even greater voice. This certainly corroborates previous research showing that women want to be respected and heard in the health care setting (Bean-Mayberry et al., 2003). However, other aspects of the women's identities may have played a role in *how* the women wanted to be heard. For example, the fact that these women were very health literate may have contributed to their desire to have a say in how budget cuts were handled. The implications of this finding are important. It suggests that policy makers and health care providers need to do more to incorporate women's perspectives, but that addressing women as a singular category is inadequate. We have said for more than a decade that patient perspectives are important, particularly when it comes to addressing the significance of terms like patient centred care (Lees, 2011; Little



et al., 2001). Yet little action has been taken to incorporate diverse groups' voices in research to truly influence the provision of health services (Frojd et al., 2011). My research is one step in the right direction, but more research is necessary.

**Chapter V.** In this chapter, I related the story of what the women experienced at their women's health centres. Specifically, the women voiced perceived strengths and weaknesses that affected how they used these services. Both of these types of patient evaluations (i.e., strengths and weaknesses) are important; on the one hand, relating the strengths of women's health centres adds to the support for maintaining (and even increasing) funding. On the other hand, describing the weaknesses also reveals places for concern and improvement. We know that the quality (or at least perceived quality) of services can have a significant effect on a patient's experiences with health care (Bowling & Ebrahim, 2005). In this case, the strengths enticed women to stay, but at times the weaknesses were often too much to overcome, and as a result some of the women stopped attending their women's health centres.

As an additional experience at women's health centres, the women spoke of the role that connectivity and community played in their use of their women's health centre. Ultimately, the women felt connected to other women and their women's health centre, and most of the experiences revealed a passion for being heard. These women were invested in their communities, and wanted to shape their own experiences. However, I would like to address an important issue in grasping the role that community played in their experiences. Regardless of how different the women's histories were, they were similar in important ways that shape their health care experiences. The women were largely privileged in terms of class, race, and in the outward expression of their



relationship status (i.e., even if they did not explicitly say they were heterosexual, they were in heterosexual relationships). They had high health literacy, and the resources to make choices. I mention these things simply to avoid essentializing what a community of women looks like. For example, today we largely recognize how limited some of our past advocacy efforts were. The needs of vulnerable and marginalized women, such as ethnic and sexual minorities or socioeconomic subgroups are often not adequately addressed under the umbrella of "women's health advocacy" (Kumanyika, Morssink, & Nestle, 2001; O'Hanlan Dibble, Hagan, & Davids, 2004); instead, a community of women is often understood as white, of the middle class, and heterosexual. In order to fully grasp what "community" means to women and the role it plays in health care experiences, we will have to employ the principles of intersectionality. Only in this way can we begin to understand "the complexity of social locations and experiences for understanding and responding to the ways in which sex and gender intersect with other variables and how these intersections contribute to unique experiences of health" (Hankivsky & Cormier, 2009).

This story about women's voices and perspectives may, again, be irrelevant for women who differ from my sample. However, this research still offers important insights. Patient perspectives and experiences are increasingly valued in health research, but these stories have had little actual impact on health care reform (Coulter & Fitzpatrick, 2000; Rodwin, 1994). My research contributes to an area that has received little focus for two decades. Further research will be needed to support my findings, and update our understandings of the services rendered at women's health centres to make them more current. What this narrative about women's experiences at women's health centres



ultimately indicates is that women's health centres are qualitatively different from other types of care, and are valued by women. The women perceived a multitude of benefits at their facilities. The implications of these findings could be extremely important, but only if they do not fall on "deaf ears" (i.e., a government that wants to make cuts regardless of what research shows us about the utility of these services). I spent some time in the introductory chapter outlining how Canadian women's health organizations were in crisis; recent cutbacks mean that women's organizations and health services are running at less than an optimal level (Varcoe et al., 2007). My findings suggest that this movement goes directly against what women want and value in their health services. It will be essential to follow up with further research and make these findings known to policy makers in Canada in order for women's health services to continue to receive funding.

**Chapter VI.** In this chapter, I related the story of how the women defined ideal women's health services. Much of this discussion simply built on the previous chapter; the women identified three factors that had already been identified as strengths of their women's health centres (i.e., focusing on issues that women alone would face, respecting women's voices, connecting with other women). Two additional aspects of ideal women's health centres were also articulated, and these were principles/factors that the women believed they had not yet received (i.e., offering unique services in a "one-stop shop" format, and incorporating specific training and philosophies of care with a focus on women). Again this work supports the notion that women's health centres are valued.

In the second half of the chapter, I discussed patterns in the women's navigation of their services more generally. These two patterns included withdrawing from care (i.e., not accessing health services), and receiving fractured care (i.e., receiving care from



multiple providers and locations). In North America, navigating health services tends to be associated with the need for high health literacy (McCray, 2005). Patients are increasingly asked to take responsibility for their health care needs and decisions, yet the health care system they are attempting to navigate is increasingly fragmented and specialized (Parker, 2000). For patients with lower health literacy, this often results in negative health outcomes and patterns of health care usage. Patients with low health literacy have less knowledge of their conditions and treatment programs, are not as capable of self-management, and are more likely to suffer from chronic disease (McCray, 2005). Additionally, patients with low health literacy tend to spend more on health care and use services more often, yet have lower rates of engaging in critical preventive health measures (McCray, 2005). As a result, some research has indicated that education may be necessary to help patients learn to navigate their health care system (Ferrante, Cohen, & Crosson, 2010).

In contrast, the women in my sample had high health literacy; many of them worked in health care settings, and most used sophisticated language when discussing issues related to women's health. However, even individuals with high health literacy can struggle to obtain, understand, and use health information (Nielsen-Bohlman et al., 2004). Because of the many differences between groups with high and low health literacy, their needs differ and research related to both populations is essential. The correlates of high health literacy generally indicate privilege and can include higher socioeconomic status, greater self-efficacy, and heightened access to care (Berkman, DeWalt, Pignone, Sheridan, Lohr, et al., 2004); these characteristics seem to epitomize my sample as well. However, women also face multiple barriers to their health care in comparison to men,



and their patterns of health care utilization differ from men's in important ways, such as using services more often, and spending more money on services (Bertakis et al., 2000). Unfortunately, not enough research exists dissecting how multiple aspects of a woman's identity impact care seeking behaviours. This makes the findings of my study particularly important

This narrative suggests that the health care system was largely perceived by these women as fragmented and source of marginalization, even for privileged women. The implications of my findings can really been seen more as a call for health care researchers to do a better job at addressing patient voices and engaging in the critical knowledge translation that will allow these voices to contribute to health care reform. Previous research has indicated a need for exploring how people with health literacy (and other types of literacy) make sense of their health services and needs (Nielsen-Bohlman, Panzer, & Kindig, 2004); there are important differences in these groups from those who do not have health literacy. However, my work also suffers in that I *only* accessed a particular intersection of women. Regardless of how important it is to also address these perspectives, it seems clear that women who experience more marginalization in general (e.g., through poverty and other minority status) will struggle even more to navigate their health services. As such, further research is required.

**Chapter VII.** In this chapter, I briefly related how different aspects of the women's identities interacted to shape their experiences with health care. Again, the women faced a gender disadvantage in relation to health status and access to health care. However, these women also largely experienced institutional privilege (e.g., through SES, health literacy, health status, etc.). Researchers have advocated for understanding the



difference between "identity" and "categories of difference" (Hankivsky & Cormier, 2009; Yuval-Davis, 2006). While identity "refers to an individual or social group's unique social location along single dimensions of multiple categories, the study of categories of difference typically entails exploration of multiple dimensions of multiple categories" (Hankivsky & Cormier, 2009, p. 5). It is essential to move away from simply exploring these categories separately and instead to explore how intersections of power contribute to women's experiences (Dhamoon, 2008). I believe I have contributed positively to the intersectional literature by examining the multiple ways these women were both privileged and marginalized. Health disparities continue to exist across North America for minority subgroups (Weber & Parra Medina, 2003), but it is imperative to avoid essentializing groups of individuals if we hope to meet the diverse needs of Canadians (and particularly Canadian women).

It is thus clear that women's identities beyond their gender matter when it comes to understanding and navigating women's health care services. If privileged women feel disempowered and left without a voice, our system of women's health policy makers, providers, and researchers have certainly not done enough to adequately address the experiences of women on the margin. Because my research is only exploratory, further work is needed to examine the experiences of different groups of Canadian women to make more concrete conclusions about how the health care system impacts the entire spectrum of individuals in our country.

## Limitations

In the preceding chapters, I addressed specific limitations (i.e., those related to the conceptualization of this project) as they arose. For example, I noted that "giving voice"



can be problematic in that it can reaffirm systems of oppression (Ashby, 2011). I discussed limitations to interpretive phenomenological analysis (i.e., the common mistakes of failing to acknowledge the fact that the stories were collected from a research interview, and attempting to do too much with the analysis; Parker, 2005). I also noted that in some cases (e.g., trying to determine education levels of a few of my participants), I clearly made my own interpretations of their experiences. For the most part, these types of limitations could be dealt with by being reflexive and transparent about my approach. Awareness that these problems exist and attempted avoidance of them were essential to address such limitations.

In addition to these smaller issues, I also alluded to several other limitations related to my methodology, and would like to discuss those in further detail here. For the most part, these limitations are not ones that simple transparency can address; instead, they are limitations that must be considered when trying to discern how trustworthy, credible, and believable these findings are. Namely, I would like to address my data collection process, my final sample, and my intersectional analysis.

With regard to my data collection process, there are several concerns that need to be addressed. In phase one of my research, I developed a survey specifically for this study to ask directors of women's health centres whether they adhered to Hills and Mullett's (2002; 2005) principles of women centred care. The validity and reliability of these operationalizations may be questionable. I used a deductive approach (i.e., I chose a model of women centred care for this study, rather than allowing the model to emerge from the data), and structured my questions such that the directors could agree or not to whether they followed these principles. As a result, the directors largely agreed with



almost every principle, and it was difficult to say anything meaningful about the "women centredness" of these facilities because of this homogeneity. In hindsight, I should have asked the directors to describe their own principles, as opposed to presenting a predetermined set to the directors for their consideration.

As a result of my survey design, and of the limited number of respondents I obtained, this data set was not optimal. However, the exercise was still useful. First, I learned about the use of family centred care from this first phase of data collection. Second, I was alerted to the fact that directors may not see a practical difference in women centred care from other types of patient focused paradigms, but that they at least believe women centred principles were being put in place in a meaningful way. Third, I was able to improve my subsequent data collection and analysis as a result of these issues. For future research to discern any meaningful difference in the mandates of hospital and community based women's health centres, and determine how women centred care is applied in Ontario, we will need to use better designed measures. We will also need to be more creative in gaining access to these research participants.

There were also a few limitations to my data collection in phase two. I have already noted the difficulty I went through to obtain even this small sample (i.e., my inability to recruit from a single physical location). In the end, I opted for online recruitment and a telephone interview with women from all over Ontario. I was unable to actually visit their individual health centres, and cannot be certain of how "accurate" the women's perceptions are. For example, Jane discussed the cuts made to her women's health centre in such a way that it seemed there were no services for women of her age group. Upon visiting the website for her facility, I realized that this was a slight



exaggeration. Unfortunately, not all of the facilities the women attended had quality websites or information available about all of their services. This lack of clarity was also a weakness noted by my participants. In other cases, a year or two had passed since the women had attended their women's health centre, and it is possible that their perceptions had changed over time. It is also possible, because things change so rapidly and often chaotically in the health care realm (Huston, 2008), that the website I visited was no longer accurate for what they had experienced.

While these issues must be acknowledged, upon closer inspection they may not be a significant concern. I was interested in what the women believed of their services, and how they had engaged with them as a result. We know that patient perceptions are important, and affect patterns of health care utilization (Bertakis et al., 2000). According to the Behavioral Model of Health Services Use (Andersen, 1995; Andersen, 2008), a person's predisposing characteristics, their "enabling resources" (e.g., knowledge of health services or social support for care-seeking), and perceived need directly impact health services use. Using this model, these women's *perceptions* about what had transpired or what was being offered were just as important as what was "objectively" being offered. In Andersen's model, "actual" health care services and other environmental factors may only indirectly impact actual health behaviors, mediated by individual factors and perceptions. As a result, I am comfortable portraying my findings as evidence of what women believe about their women's health centres, and believe this research is still pertinent to understanding how services are accessed in Ontario.

Another limitation to my data collection was my lack of validation of the individual vignettes I constructed and IPA I conducted. Only two women even contacted



me about the transcripts I had sent. As a result, these findings must be acknowledged as *my interpretation* of how events in these women's lives unfolded. Member checking is generally seen as an integral part of improving the accuracy and transferability of research (Yanow & Schwartz-Shea, 2006). However, member checks can also generate more data, which ultimately also require analysis and interpretation. As a result, member checking may not be the direct form of validity assessment we believe it to be (Pope & Mays, 2006). Regardless of the many advantages and disadvantages to the member checking process, it is still a limitation that must be acknowledged, and may impact that credibility and fidelity of my findings. For future research to build on any of these findings and apply them to larger samples, evaluative criteria must be addressed more systematically.

Additional limitations existed regarding the sample I arrived at. I have already explained in detail how these women were privileged (and simultaneously marginalized in specific ways) in comparison to the larger Canadian or Ontario public. For example, these women were largely educated and of the middle class, were highly health literate, and had satisfactory health status. They were also largely White and, minimally, maintaining an outward appearance of heterosexuality. On the other hand, more of these women lacked a general practitioner than the national and provincial average (Hutchison, 2010). Most of the women also felt that they had been marginalized by their age. For the younger generation (i.e., 20 to 30 years old) this meant they felt they had been judged for their lifestyle or that their age precluded them from being serious about their health services. For the older women (i.e., 50 to 60 years old), this meant a belief that health services were not being directed at them and instead were focused on those of child



bearing years. Unfortunately, I was not able to interview women of other ages to determine if it was just these age groups, or if all women feel that age is a marginalizing factor. As a result, the women in my sample may not be representative of Ontario women, nor of the women who access women's health services on a regular basis. This fact must be taken into consideration when attempting to apply my findings at a systems level or to make recommendations related to Ontario health policy. However, this project was exploratory in nature and has highlighted many areas for future examination.

Highly related to these sampling issues, and my ability to make conclusions for Ontario women, is a final limitation regarding my sample and analysis. I chose not to disclose the specific locations and health centres accessed by my participants. I did this because I revealed a significant amount of personal detail about my participants, and wanted to protect their identities. However, this is an important limitation that could affect the applicability of my findings, as there are regional disparities for health services more generally, and women's services specifically, across Ontario (Reid , Freeman, Thind, Stewart, Brown, et al., 2009; Tepper et al., 2005). Generally speaking, the greatest disparities occur for women in rural and northern Ontario locations (Tepper et al., 2005). None of my participants came from northern Ontario, and only one woman lived in a rural location (however, this location was not entirely remote). Instead, the women in my sample represented central and southwestern Ontario, and the greater Toronto area. Two women accessed the same women's health centre, but lived in different cities (otherwise there were no repeats).

Before any of my findings can be incorporated into provincial and national policy, it will be critical to obtain accurate data regarding the ability for women to access health



services in every region of Ontario. However, accurate data of this nature are difficult to secure (Reid et al., 2009). Future research will need to do a better job of addressing this problem and disseminating these findings to communities outside of the immediate medical community. These issues mean that my findings may not be generalizable beyond the experiences of these seven women. While generalizability was not one of my most important goals, it is still significant in terms of what my findings mean for the province of Ontario.

Lastly, I would like to address the limitations to my intersectional analysis. According to Lorber, "a sample must be heterogeneous in order to fully explore how multiple categories intersect to form unique social locations" (2006, p. 450). Another concern is taking into consideration the experiences of those who are marginalized, rather than privileged (Hankivsky & Cormier, 2009). Although my sample was somewhat homogeneous and privileged in many ways, by virtue of their gender, the potential lack of access to providers in their areas, and some important social differences that I addressed in the last chapter, these women have been marginalized by the health care system. As such, I am comfortable with my sample and the conclusions I can make. However, this is an important caution for future researchers wishing to incorporate intersectionality into their work; the final sample is crucial to the approach.

## **Final Thoughts**

Ultimately, the narrative I have presented is largely based on patient perceptions. The advantage to exploring these perceptions is that many providers lack insight into the experiences of their patients (Morris, Devlin, & Parkin, 2007); this research may offer places for providers to start. Patient criticisms in particular often imply that providers are



simply out of touch with what their patients expect (Rozenblum, et al., 2011), and so it is important to recognize that these criticisms reflect subjective evaluations. While these criticisms may also represent *objective* evaluations (i.e., anyone appraising the quality of care would make these same judgments), they must be understood as being relevant to these particular women's expectations (i.e., these women are not necessarily representative of all women). Patients often make judgments about their health care services in relation to prior experiences (Chapple, Campbell, Rogers, & Roland, 2002), and it was clear that this was the case with my sample of women as well; many of the women spoke of their services at their women's health centre in relation to those they had experienced outside of it.

One of the most important implications of having the patients elucidate perceived experiences is that it is clear that more research is needed to determine how women's health centres have evolved over the years and how women's needs are, or are not, being met. For example, there has been little research exploring the actual services offered and women's perceptions of them since the 1990s when women's health centres first opened. In just two decades, the funding devoted to addressing women's health needs is disappearing. This may account for the seeming lack of development over the last 20 years, but at this point it is difficult to say. Hyde (2008) has suggested that women's health centres have had to adapt as society has changed its perceptions and understandings of women's health (i.e., with the Women's Health Movement running out of steam, largely impacted by diminished funding). That is, women's clinics have evolved and changed from the initial concept of feminist health clinics that were local and independent from hospitals (e.g., Weisman, Curbow, & Khoury, 1995) to services



that are often offered in hospitals. I believe that we may have to take a closer look at the history of women's health centres over the last 40 years to truly understand philosophical changes. A lack of empirical evidence makes this task difficult. I hope that my research has shed some light on how women's health services are experienced by the women themselves, shows that they appreciate services directed at women specifically, and validates the inclusion of women's health initiatives in Ontario and Canada at large. Continued cutbacks will cripple women's services, and research of this nature can hopefully put an end to any further devaluing of women's health in this province.



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#### APPENDICES

APPENDIX A: Recruitment Notice



# YOU ARE INVITED TO PARTICIPATE! HAVE YOUR VOICE HEARD!

Women's health care is an important issue in Ontario. We would like to know what <u>YOU</u> think about your health care services

at Women's Health at St. Joseph's Health Care, London If you agree to participate, you will be asked to complete a brief interview. Your time will be compensated.

# Please contact Barat Wolfe at 519-253-3000 ext. 4704 or wolfeb@uwindsor.ca

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#### APPENDIX B: Women's Health Centres in Ontario

#### Barrie

Simcoe Women's Wellness Centre 80 Bradford St., Suite 232 L4N 6S7 705-721-5875 swwc@csolve.net

#### Etobicoke

Rexdale Community Health Centre 8 Taber Road M9W 3A4 416-744-0066 or -6312

#### Hamilton-Wentworth

Women's Centre of Hamilton-Wentworth 75 McNab St. S., 3<sup>rd</sup> Floor L8P 3C1 905-522-0127 womenscentre@on.aibn.com

#### Kingston

Queen's University Women's Centre 51 Queen's Crescent K7L 3N6 613-533-2963 www.ams.queensu.ca/wmncntr

#### London

Women's Health of London Contact: Jodi Tucker (Office Manager) 339 Westminister Ave. (400 Dundas St.) N6C 4V3 (N6B 1V7) 519-645-0421

Women's Ambulatory Health Services St. Joseph's Health Care – St. Joseph's Hospital 268 Grosvenor St. Box 5777 N6A 4V2 519-646-6129 www.sjhc.london.on.ca

Women's Health Care Centre London Health Sciences Centre – Victoria Hospital



Professional Block, Room E3-600 800 Commissioners Rd. E. Box 5010 N6A 5W9 519-685-8500 ext. 58204 www.lhsc.on.ca/womens/

#### **Niagara Falls**

Niagara Feminist Centre for Alternative Health 4590 Roseland Crescent L2J 1R9 905-358-8760

#### Ottawa

Ottawa Hospital – Obstetrics and Gynaecology Newborn care and Women's Health Services 501 Smyth Road K1H 8L6 613-722-7000 http://ottawahospital.on.ca

Women's Place 755 Somerset St. W. K1R 6R1 613-231-5144 ext. 7915 wplacef@storm.ca

#### **Owen Sound**

Women and Child Care Services Grey Bruce Health Service – Owen Sound Hospital 1800 8<sup>th</sup> St. E. Box 1800 N4K 6M9 519-376-2121 www.qbhs.on.ca

#### Peterborough

Women's Health Care Centre Peterborough Regional Health Centre 157 Charlotte St. K9J 2T7 705-743-2121 whcc@prhc.on.ca www.prhc.on.ca/WomensHealth

Women's Health Care Centre 69 George St. N.



K9J 3G2 705-743-4132

Women's Health Care Centre 1 Hospital Drive K9J 3G2 705-876-5117 whcc@nexicom.net www.kawartha.net/whcc/wom.htm

#### Sault Ste. Marie

Women's Health Centre 240 McNabb St. P6B 1Y5 705-759-5552

#### Sudbury

Sudbury Women's Centre 324F Elm St. W. P3C 1V8 705-673-1916 swc@isys.ca

#### Toronto

Medisys' Women's Executive Health Centre 95 St. Clair Ave. W., 12<sup>th</sup> Floor M4V 1N6 416-926-2698 www.medisys.ca/en/women-health-centre.htm

Immigrant Women's Health Centre 489 College St., Suite 200 M6G 1A5 416-323-9986 iwhc@volnetmmp.net

Women's Health Centre St. Joseph's Health Centre Morrow Wing on Ground Floor 416-530-6850 kaldad@stjoe.on.ca www.stjoe.on.ca/svc\_womens\_health.html

Women's Health in Women's Hands Community Health Centre 2 Carlton Street, Suite 500



M5B 1J3 416-593-7655 whiwh@web.net

Toronto Hospital Women's Health Program 200 Elizabeth St., EN-1-222 M5G 2C4 416-340-4185 dstewart@torhosp.toronto.on.ca

College Street Women's Centre for Health Education and Counselling 489 College St. M6G 1A6

St. Michael's Hospital Women's Centre 30 Bond Street M5B 1W8 416-867-7480

Hassle Free Clinic – Women/Trans Clinic 66 Gerrard St. E., 2<sup>nd</sup> Floor M5B 1G3 416-922-0566 www.hasslefreeclinic.org/DirectoryWomen.php

Women's College Hospital 76 Grenville St. M5S 1B2 416-323-6400 www.womenscollegehospital.ca

#### Waterloo

Waterloo Women's Health Clinic 99 Regina St. S. N2J 4V3 519-883-2318

Windsor

Women's Health Centre 1400 Provincial Road 519-250-6990 www.drzsherman.com



#### APPENDIX C



### CONSENT TO PARTICPATE IN RESEARCH

#### Her choice, her voice: An exploration of women-centred health care

You are asked to participate in a research study conducted by Barat Wolfe, a Ph.D. student, and her faculty supervisor, Dr. Fuschia Sirois from the Department of Psychology at the University of Windsor. These results will contribute to Ms. Wolfe's doctoral dissertation.

If you have any questions or concerns about the research, please feel to contact:

Primary Investigator: Barat Wolfe: 519-253-3000 ext. 4704, wolfeb@uwindsor.ca

Faculty Supervisor: Dr. Fuschia Sirois: 519-253-3000 ext. 2224, fsirois@uwindsor.ca

#### PURPOSE OF THE STUDY

Recently, researchers and practitioners have promoted a new health service delivery option in women-centred care. There are currently many ways in which women-centred care could be practiced, but little is known about how women-centred care is practiced in Ontario. The purpose of this study is to create a profile of each Ontario women's health centre based on principles of women-centred care, and explore the similarities and differences among them.

#### PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

1. Complete a brief survey which deals with the principles of women-centred care. This survey takes 15 - 20 minutes to complete, although individual completion times may vary depending on your computer system.

2. If you are willing, allow your health centre's name to be associated with my findings. If you agree, we would identify your facility in our findings. If not, any information you give would be completely confidential. You can withdraw this consent to be identified at any time during the research project prior to publication.



After this portion of the study has been completed, there will be an opportunity for your health centre to be involved in a second portion of this study. You will be asked at the end of this survey if you are willing to be contacted again regarding this second part, which involves no work by you, but would involve me interviewing women from your health centre.

#### POTENTIAL RISKS AND DISCOMFORTS

There are no known risks associated with this research project. Any information you give will be confidential unless you agree to have the identity of your health facility associated with the findings of this project. We want to create a profile of each Ontario women's health centre; one of the goals of this project is thus to understand models of women-centred care from your perspective and to use your feedback to identify models of care that are appropriate for Ontario; we will not be assessing whether you are women-centred or not, but rather exploring how you are women-centred.

#### POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

You will gain the direct benefit of receiving the individual profile created for your health facility, which can be used on your website or for marketing purposes. You will also be contributing to an area of research that is underdeveloped. To date, there is no listing for women's health centres in Ontario; this project will produce such a listing and will inform women's health centres about the model of care other centres are following in Ontario. It is hoped that this project will lead to a greater understanding of women-centred care and its principles, and in the process inform health researchers and policy makers on how to improve health care for women in Ontario (and Canada).

#### PAYMENT FOR PARTICIPATION

You will not be compensated for your participation in this project.

#### CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. Several steps will be taken to ensure the confidentiality of the survey data you submit. All incoming surveys will be stored on a secure University of Windsor server on a password protected computer, and be accessible only by the researchers. Following the guidelines of the Canadian and American Psychological Associations, data will be retained for a period of five years after publication in a secure place, after which time it will be disposed of in a secure manner (e.g., shredded or electronically deleted).

#### PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.



#### FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

After the data has been collected and analyzed, your profile and a summary report, with no identifying information, will be made available to you. You will then have the opportunity to give feedback regarding the findings. This summary will be made available via email by February 2010.

#### SUBSEQUENT USE OF DATA

This data will be used in subsequent studies.

#### **RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

#### SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Barat Wolfe, M.A.

Fuschia M. Sirois, Ph.D.

Department of Psychology

University of Windsor



APPENDIX D: Online Survey with Directors of Women's Health Centres

#### Study: Her Choice, Her Voice: An Exploration of Women-Centred Health Care

You are invited to participate in a research study to explore the principles of womencentred care in Ontario, and to create a profile of each Ontario women's health centre based on these principles. If you agree to participate, we ask you to complete the following online study. If you have questions about this process, or difficulty completing the survey, please contact Barat Wolfe at wolfeb@uwindsor.ca of 519-253-3000 ext. 4704.

Please enter your email to begin the survey. You may only complete the survey once.

Email Address :

In addition, I agree to the name of my facility being used in the findings of this study. I understand that this consent can be withdrawn at any time by contacting the researchers at wolfeb@uwindsor.ca or 519-253-3000 ext. 4704.

I Agree

No Thank You

1. Name of your women's health centre:

2. How long have you been in operation?

3. Do you charge an extra fee for women to participate in this health centre?

Yes

No

4. If yes, how much is this fee and what services are provided to the women in return?

5. Do you receive public funding?

Yes

No

6. If yes, from who?

7. If no, how is your organization funded?



220

8. Do you offer primary health care?

Yes

No

9. What population of women do you serve (e.g., all women, women at risk, aboriginal women, women with their children, immigrants)?

10. How do you define "women-centred"?

11. Do you define your women's health centre as "women-centred"?

Yes

No

12. If no, how do you define this women's health centre?

13. For what purpose does your health centre exist?

- 14. What is your health centre's explicit mandate?
- 15. Who decided on this mandate?
- 16. Which of the following principles apply to your women's health centre?

Please check all that apply:

- 1) Treats women with respect
- 2) Acknowledges women's experiences
- 3) Acknowledges/accepts diversity of women
- 4) Acknowledges women as primary caregivers and child rearers
- 5) Recognizes that women often have greater difficulty accessing health care
- 6) Considers the impact of social factors
- 7) Considers the impact of economic factors
- 8) Considers the impact of societal factors



- 9) Considers the impact of environmental factors
- 10) Considers the impact of cultural factors
- 11) Considers the impact of other factors (please specify):
- 12) Recognizes social gender imbalances
- 13) Gives women information to makes informed choices
- 14) Gives the right to ask questions and consider appropriate medical alternatives
- 15) Allows for cooperation with mutually supportive health professionals
- 16) Encourages collaboration with health care providers
- 17) Allows for self-determination
- 18) Considers contributions of other health care providers
- 19) Is gender sensitive

# 17. For each of the options you chose, and which appear below, please briefly describe how your centre accomplishes each principle in the text box below. Please place the corresponding number before each comment.

- 1) Treats women with respect
- 2) Acknowledges women's experiences
- 3) Acknowledges/accepts diversity of women
- 4) Acknowledges women as primary caregivers and child rearers
- 5) Recognizes that women often have greater difficulty accessing health care
- 6) Considers the impact of social factors
- 7) Considers the impact of economic factors
- 8) Considers the impact of societal factors
- 9) Considers the impact of environmental factors
- 10) Considers the impact of cultural factors



- 11) Considers the impact of other factors
- 12) Recognizes social gender imbalances
- 13) Gives women information to makes informed choices
- 14) Gives the right to ask questions and consider appropriate medical alternatives
- 15) Allows for cooperation with mutually supportive health professionals
- 16) Encourages collaboration with health care providers
- 17) Allows for self-determination
- 18) Considers contributions of other health care providers
- 19) Is gender sensitive

**18.** Please briefly describe how your centre accomplishes each of the principles listed above using the corresponding numbers for each.

**19.** Are there any barriers to providing women-centred care? Please describe them:

20. It's been a challenge to locate all of the women's health centres in Ontario without an explicit listing, and we would like to gain the perspectives of as many facilities as possible. We would ask you to identify other women's health centres in Ontario you know of here:

#### 21. Would you like to add anything else?

This is an ongoing project that involves a second component to the research. If you are willing, we would ask that you agree to be contacted again after this data has been collected and analyzed to see if you are interested in a second portion of this study. If you agree to be contacted again, another letter of information will be sent regarding the second part of the study, and you can make the decision then whether or not you want to participate.

Do you agree to be contacted again to see if you are interested in participating in a second part of the research project?

I Agree

No Thank You

Thank you - your time and thoughtful responses are greatly appreciated.



#### APPENDIX E

#### Profile of Women's Health Centre #1

Name: Women's Health Care Centre: [Central Ontario] Regional Health Centre (WHCC) Location: Hospital - Central Ontario Population of women served: All women

#### Self-define as women centred: Yes

**Definition of women centred care:** With information and support women can make safe, informed choices about their health. The right to make informed choices about reproductive health without judgment.

#### Hills and Mullett's (2005) principles adhered to:

All except:

- 11 Considers the impact of other factors
- 15 Allows for cooperation with mutually supportive health professionals

#### How WHCC ensures these principles are met:

- Provide options and allow the client to choose what works best for them
- Facilitate groups that allow women to share their experiences
- Wheelchair accessible space and exam table
- Exam table also accommodate larger women
- Interpreters are utilized when needed. Some pamphlets available in different languages
- Breastfeeding clinic, large parenting section in Resource Library
- Provide cabs, allow for some drop in or off hours care, 2nd separate wait area (private), hassle free pregnancy testing, supply condoms to sex trade workers
- Working from a Feminist perspective
- Public Lending Library covering most Health care issues
- Belong to many coalitions and networks in the area (i.e., [Central Ontario] Domestic Abuse Network

**Purpose of facility:** To enable women to enhance their quality of life and to make choices in their health care in a positive and welcoming atmosphere. The centre is dedicated to the wellbeing of ALL women in the communities we serve.

**Mandate of facility:** Health care should be accessible and available to ALL women. Women have the right to seek and maintain wellness as defined by them. Women have the right to make choices related to their social, emotional, physical and spiritual wellbeing. This includes the right to make informed choices in all aspects of sexual and reproductive health. Health care should include alternatives to traditional medical options. Education and empowerment are essential for women to achieve their full health potential.

Biggest challenges: Maintaining funding in the health care sector



#### APPENDIX F

#### **Profile of Women's Health Centre #2**

**Name:** Women's Health in Women's Hands Community Health Centre (WHIWH) **Location:** Community Centre – Toronto

**Population of women served:** Black women and women of colour from South Asian, African, Caribbean and Latin American communities

#### Self-define as women centred: Yes

**Definition of women centred care:** We are committed to working from an inclusive feminist, pro-choice, anti-racist, anti-oppression, and multilingual participatory framework in addressing the issue of access to healthcare for our mandated priority populations encompassing gender, race, class, violence, sexual orientation, religion, culture, language, disability, immigration status and socio-economic circumstances.

#### Hills and Mullett's (2005) principles adhered to:

All

Others: Recognizes racism and other oppressions including sexual orientation and gender identity as determinant of health

#### How WHCC ensures these principles are met:

- Delineated in our mandate and working principals and form the basis for our model of care and I cannot address them all separately as they are intertwined
- Recognize that the well-being of our priority populations is impacted by their gender, race, class, violence, sexual orientation, gender identity, religion, culture, disability, immigration status and socio-economic circumstances
- Committed to constantly challenging our assumptions and analyses and are committed to being advocates for change in our communities
- Embracing social justice initiatives
- Disrupting, overturning and reconstructing oppressive values, definitions, policies, institutions and relationships
- Challenging each other to continue the learning
- Maximizing client resources/Access to resources
- Reducing power inequities in client-worker relationship
- Unmasking primary structures of oppression
- Fostering activism within social movements
- Encouraging behaviors leading to personal and political change

**Purpose of facility:** WHIWH inclusive multidisciplinary services include primary medical care for all women from the age of 16, mental health support programs with individual and group counseling, self advocacy programs, health promotion and education programs, Pre and Post Natal Care programs, HIV-AIDS Prevention, Support and Care, healthy living activities, support groups, supportive self care activities and a resource information center. Our staff complement includes physicians, nurse



practitioners, nurses, mental health therapists, health promoters, community health workers, a dietician, a chiropodist and a social worker.

**Mandate of facility:** The mandate of Women's Health in Women's Hands [WHIWH] Community Health Centre is to provide primary health care to Black Women and Women of Colour from the Caribbean, African, Latin American and South Asian communities in Metropolitan Toronto and surrounding municipalities. We are committed to working from an inclusive feminist, pro-choice, anti-racist, anti-oppression, and multilingual participatory framework in addressing the issue of access to healthcare for our mandated priority populations encompassing gender, race, class, violence, sexual orientation, religion, culture, language, disability, immigration status and socio-economic circumstances.

**Biggest challenges:** Disparities exist in disease prevalence particularly if we consider the intersection of race, class and gender in the discussion. Breast cancer, prostate cancer, diabetes, end-stage renal disease, hypertension, and HIV/AIDS are a few of the major diseases that are disproportionately prevalent on a global scale among members of Black communities and communities of colour. Although Canadian research is lacking in the areas of ethnic and racial disparity in disease prevalence, most of these conditions are likely caused by the interaction of genetic factors, socioeconomic status, lifestyle habits, and environmental influences that include racism, sexism, oppression, and inappropriate or inaccessible health care systems. Without question, the health status of any community will have a direct impact on the ability of that community to thrive, contribute and develop.

Adequate institutional mechanisms and resources are required for the successful achievement of inclusive racist free policies and programs. If we are to develop a system of inclusive health care we are required to create health care policies and programs that reflect the realities of all citizen's lives, including experiences of racism and the subsequent impact on one's health.

1. Gender inequalities and power imbalances:

Women are dis-empowered, subservient and excluded from decision making. Women are taught to leave decision making to their male partners/family members or community/state. Patriarchy sustains double standards for men and women – food, schooling, economic opportunities, inheritance, etc.

2. Violence against women:

All types of violence or threat of violence and fear of abandonment act as significant barriers for women. Trafficking of women and young girls for prostitution and sexual exploitationary - a form of violence against women that is fueled by poverty, international tourism and globalization.



3. Homophobia:

Homosexuality is unacceptable and seen as a moral aberration with some communities reacting violently against those who are presumed to be homosexual/lesbian – e.g. Fanny Ann (Sierra Leone). Fear of homophobia causes gays/Lesbians to live underground/in the closet. Most choose to keep their sexual orientation a secret. Lack/Limited access to information, supports and services for lesbians/gays.

4. Service providers have limited information/understanding of factors (social, economic, cultural, religious forces) and how they interact to create multiple oppressive systems – culturally inappropriate and inaccessible programs and services

Programs must:

- Incorporate cultural values, beliefs, norms and practices
- Recognize that individuals and communities are products of their contexts/cultures
- Propose actions centered on peoples' cultural references/mentalities including religious, cultural and ethical values, taboos, family and power structures, gender roles and relationship norms, child rearing practices, monogamous/polygamous marriage systems, sexual norms and legitimized practices, representations of health/disease, life/death, time and conceptions of the future
- This will provide the framework and base for building relevant and sustainable programs and services for black women and women of color



#### APPENDIX G

#### Profile of Women's Health Centre #3

Name: Women's Ambulatory Health Services at St. Joseph's Health Care (WAHS) Location: Hospital – London Population of women served: All women NOTE: Women's Health Centre closed on June 29, 2012 (http://www.stjoe.on.ca/programs/family/women.php)

#### Self-define as women centred: Yes

**Definition of women centred care:** Focused on the specific needs of women within an environment that is supportive of women

#### Hill and Mullett's (2005) principles adhered to:

All except:

11 – Considers the impact of other factors

#### How WHCC ensures these principles are met:

- Patient rights document present in all areas
- Clinic spaces are all centred on family needs
- Provide support that is focused on different groups (i.e., pregnant teens, ethnic group tours, etc.)
- Advanced practice nurses, lactation consultants, social workers and dieticians available to provide support as required Hospital funded via Ministry of Health

Purpose of facility: Hospital and health care for the community

Mandate of facility: Outlined by the Accountability agreement with the LHIN

**Biggest challenges:** Difficult to support families when external restrictions are put in place (i.e., limited visitors during H1N1, women were unable to bring families with them for appointments as the Ministry imposed total number of accompanying visitors)



#### APPENDIX H

#### Profile of Women's Health Centre #4

Name: Grey Bruce Health Services Women and Child Care Unit (WCCU) Location: Hospital – Owen Sound

**Population of women served:** Perinatal women all stages antepartum to postpartum, women having gyne surgery and other women admitted to hospital for a variety of medical or surgical reasons

#### Self-define as women centred: No

**Definition of women centred care:** Women centred is not a term we use - we typically use family centred. Women centred would mean ensuring care and treatments are appropriate for women, research and trials included women to establish findings, the whole woman considered in treatment and plan of care - emotionally, socially, physically **Definition of family centred care:** There is movement within the hospital to move to a patient centred approach. Family centred care is the norm for us - women centred is essentially synonymous

#### Hill and Mullett's (2005) principles adhered to:

All except:

- 11 Considers the impact of other factors
- 12 Recognizes social gender imbalances
- 19 Is gender sensitive

#### How WHCC ensures these principles are met:

- All people are to be treated with respect including women
- Reason for attending hospital and past experience is explored, used to guide care
- We take into consideration cultural, religious, age, etc. differences and work with the women and families to identify and meet different needs
- As a family centred we encourage parents to remain with admitted children and provide a place for them to sleep, we encourage all admitted women postpartum and other to have a support person remain with them for aid and support, we structure appointments to coincide with other appointments when possible and link to community supports as needed
- Combine appointments, evening appointments, phone consultations occasionally
- Have social workers to assist with social factor challenges
- All staff consider age, stage, economics, etc. in care

Purpose of facility: Provide acute, secondary health care - part of community hospital

**Mandate of facility:** part of the general hospital, we do not have a unique mandate for the unit. Board of hospital ultimate approval body

**Biggest challenges:** No challenges, for primary care women's health centres, funding is a challenge



#### APPENDIX I

#### **Online Recruitment Notice**

# Research participants needed: Women's experiences with health care in Ontario

Hello! I am a Ph.D. student at the University of Windsor conducting my dissertation on women-centred health care in Ontario.

I am recruiting <u>women who attend women's health centres in Ontario</u> to participate in an interview. The purpose of my research is to explore Ontario women's experiences with women's health centres to better understand your health needs and expectations about your health care. I am interested in why you attend a women's health centre, what you perceive to be the strengths and weaknesses of the care you receive there, and whether attending a women's health centre has helped you better understand your health needs as a woman.

I would like to recruit <u>10 to 20 women</u> for my study, which has been approved by the Research Ethics Board at the University of Windsor and the Office of Research Ethics at the University of Western Ontario. You will be asked to complete an hour long interview (either over the phone or I will travel to interview you at your convenience) and <u>you will receive \$20 for your time</u>. All information will be kept confidential. I am hoping to complete my interviews <u>by the end of May</u>.

Research regarding women's experiences with health care is an important issue in Ontario. Here is a chance to have your voice heard! If you are interested in participating, please email me at wolfeb@uwindsor.ca or contact me at 519-253-3000 ext. 4704 (the Occupational Health and Well-being Research Lab at the University of Windsor) so that we can set up an interview time and location that is convenient for you.

Thank you and I look forward to hearing from you soon!

Barat Wolfe, M.A. Ph.D. Candidate Department of Psychology University of Windsor wolfeb@uwindsor.ca 519-253-3000 ext. 4704



#### APPENDIX J



## LETTER OF INFORMATION AND CONSENT FOR PARTICIPANTS

Her choice, her voice: An exploration of women-centred health care

Principal Investigator:

Barat Wolfe, B.Sc., M.A. Department of Psychology University of Windsor Telephone: (519) 253-3000 ext. 4704 Email: wolfeb@uwindsor.ca

#### Introduction:

You are being invited to participate in a research study to understand how women are experiencing health care in Ontario. This letter contains information to help you decide whether or not to participate in this research study. It is important for you to understand why this study is being conducted and what it will involve. If you have any questions or concerns about the research, please feel free to contact Barat Wolfe at the number or email provided above.

#### Eligibility:

You must be 18 years old and speak English to participate in this study. You must also access health care services from a women's health centre.

#### **Research Procedures:**

If you agree to take part in this study, we will ask you to participate in an interview that lasts about 1 to 1.5 hours. The purpose of this interview is to find out what you think about the health care you receive at your women's health centre and whether this care has helped you better understand your health needs as a woman. This interview will be audiotaped and transcribed, and the researcher will take notes during the session.



#### **Voluntary Participation:**

Participation in this study is voluntary. You may refuse to participate, or refuse to answer questions with no effect on your status as a patient or your future medical care.

#### **Compensation:**

If you attend the interview you will receive \$20.

#### Benefits:

While this study may not result in any direct benefit to you, it may help to better our understanding of how women's health care is being offered in Ontario. You will be able to offer feedback about your services that can be given in summary form to the director of your health facility to potentially improve how health care is offered at your health centre.

#### <u>Risks:</u>

There are no known risks to your participation in this study.

#### **Confidentiality:**

Any information obtained from this study will be kept confidential. In the event of publication, the data cannot be linked back to you personally. The transcribed responses from the audiotape of your interview will be stored on a secure, password protected computer that is only accessed by the researchers. After completion of the study, data will be archived on storage disks and stored in a locked room for five years after any papers arising from this project have been published. After this time, the data will be destroyed.

Representatives of the University of Western Ontario Health Sciences Research Ethics Board may require access to your study-related records or may follow up with you to monitor the conduct of the study.

#### Estimate of participant's time and number of participants:

The interviews will take about 1 to 1.5 hours. Up to 20 other women will be interviewed.

#### **Contact Information:**

If you would like to receive a copy of the overall results of the study, or if you have any questions about the study, please feel free to contact the Principal Investigator at the contact information provided above. The data will also be available online. Click on "participants or visitors" and follow the link from the title of this study.

Web address: www.uwindsor.ca/reb/study-results



Date when results are available: August 2011

If you have any questions about your rights as a research participant or the conduct of the study you may contact:

Dr. David Hill, Scientific Director Lawson Health Research Institute

519066706649

You do not waive any legal rights by signing the consent form.

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Date:

Signature of Research Participant:

Name of Participant (Printed):

Signature of Person Obtaining Consent:

Name of Person Obtaining Consent (Printed):



#### APPENDIX K

#### **Interview Agenda**

Tell me about yourself. Tell me about your health, and your health care needs (i.e., multiple dimensions of each woman's identity).

What value to you place on your health care?

Tell me about the women's health centre you are attending/did attend.

How have you experienced health care? What services have you accessed?

Are you familiar with the term "women centred care"? How do you define women centred care? Are you familiar with the term "family centred care"? How do you define family centred care?

Do you believe you are currently receiving women centred care? Why are or why not?

How did you come to utilize women centred care? How did you hear about it?

What were the steps that led you to using women centred care?

Why do you use women centred care?

What are the benefits of using women centred care?

What are you getting out of women centred care that you cannot/were not/will not get from other medical care?

What are the weaknesses of this care?

How would you evaluate your women centred care?

How satisfied are you with your care/services?

How can your health care providers offer services to better suit your needs?

How does your social identity affect your experiences with health care services?

How has using women centred care changed your perspective or understanding of your own health?

What else would you like to add?



#### APPENDIX L



#### Transcriptionist Confidentiality Agreement

#### Her choice, her voice: An exploration of women centred health care

#### **CONFIDENTIALITY AGREEMENT**

I \_\_\_\_\_\_\_(please print name) understand that all of the information contained in the audio tapes/files that I will be transcribing is strictly confidential, and under no circumstances am I allowed to disclose it to anyone. I understand that all transcriptions and audio data should be kept in a locked cabinet, or if electronic, password protected and stored on a secure computer. No unauthorized persons should have access to the transcription or audio data. I will destroy the audio and transcription data as soon as they have been sent to the researcher and are no longer needed.

(Transcriber)

(Date)

(Principal Researcher/Witness)

(Date)



Superordinate themes	Sub themes	Transcript location	Identifier
Dissatisfaction	Perceived weaknesses	2.4	"Old fashioned"
		2.26	"Taking responsibility" vs. "Trouble maker"
		2.33	"Cut most of services"
		8.12	"Patients do not come first"
	Feeling marginalized	1.34	"Didn't care"
		4.3	"Women's health doesn't matter"
		7.11	"I'm not heard and I'm not important"
		8.1	"Frustration" and "Not sure what change could be"
Seeking Alternatives	How she got there - Through friends	6.3	"A friend"
		6.24	"Would have bumped into it" and "Sharing"
	A role for women in decision making	1.26	"There was no consultation"
		3.1	"Advocacy"
Perceptions of Care	Strengths of women's health centre	2.1	"Wide range" and "Excellent"
		2.11	"Nurse practitionerreally good" "Mountain of info."
		3.19	"Newsletter outreach"
		3.25	"They understood"
		6.16	"An alternative"
		10.33	"Empowered"
	Weaknesses of women's health centre	3.9	"Aren't available"
		7.13	"Not adequate at moment"
		7.26	"No money and staff"
		8.21	"Nothing for aging women"
Navigating the system	Going without services	6.33	"I haven't gone"
Understanding the system	Understanding of WCC	4.34	"Politically correct"
2		9.18	"Not just about physical health"
	Ideal health centres	9.1	"Opportunity" and "Mandate"
		9.33	"Better coordination of services"
	Family different from women centred care	4.35	"In theory"
		5.12	"Family – don't know why talk about it that way"
		5.18	"Call it women"
Role of Self- Identity	Age	8.28	"I feel invisible"
	Location	1.13	"Isolating"
	Class	12.15	"Too expensive"
	Health	4.25	"Depression"
	Understanding health needs because of WCC	11.15	"What was happening to our emotions"

APPENDIX M: Participant 1 Analysis Table



Superordinate themes	Sub themes	Transcript location	Identifier		
Anger and					
Mistrust	Health care as a battle ground	3.3	"Jumped through hoops" and "Services in the toilet"		
		7.14	"Think they're gods" and "Steamroller"		
		8.32	"I refer to it as war"		
		9.1	"Overloaded"		
	Feeling marginalized		"When you're sick, you can't advocate for yoursel		
		9.9	"No advocacy, at their mercy"		
		10.31	"Treat you like the masses"		
Seeking	How she got there – through work	1.1.6			
Alternatives	contacts	1.16	"Serving on same committee"		
	Need for involvement	6.3	"Nothing happens without my voice"		
		7.4	"Squeaky wheel gets the oil"		
		7.9	"Fought the good fight"		
		13.24	"Instant support group"		
Perceptions of					
Care	Strengths of women's health centre	2.5	"Services available"		
		2.24	"Painless paps" and "Library good"		
		14.21	"Healing not just physical"		
	Weaknesses of women's health centre	1.27	"Needed referral"		
		2.17	"Not getting word out" and "Younger women"		
Navigating the system	Going without services	1.22	"Working on that"		
Understanding			"No point of reference" and "Haven't heard that		
the system	Understanding of WCC	4.27	before"		
		5.23	"Pain-free procedures"		
	Ideal health centres for women	11.27	"Our bodies so different" and "Choice"		
	Family different from women centred care	3.32	"Family as whole"		
Role of Self- Identity	Age	8.3	"We're aging"		
		8.12	"I'm aging"		
	Relationship status	6.1	"Single parent"		
	Work and Education	1.16	16 "Serving on hospital committee"		
	Health	10.8	"Stroke survivor"		

# APPENDIX N: Participant 2 Analysis Table



Superordinate themes	Sub themes	Transcript location	Identifier		
Dissatisfaction	Perceived weaknesses	1.23	"Don't feel comfortable"		
		3.5	"Wait times" and "Have to take kids to emerg"		
		3.29	"So rushed"		
		8.5	"I'm not satisfied"		
	No services	1.4	"It's been three years"		
Seeking		1.20	((1/)		
Alternatives Perceptions of	How she got there – word of mouth	1.36	"It's really confusing to access" "Available – awesome" and "More comfortable with		
Care	Strengths of women's health centre	1.16	a woman"		
		4.11	"I don't feel rushed" and "Patient centred"		
		5.22			
	Weaknesses of women's health centre	5.8	"Haven't seen anything women centred"		
		5.22	"Not a lot of were to go" and "It's a maze"		
		7.6	"Can't go if you're over 26" and "Huge thing that's missing"		
Role of Community	Advocacy	5.3	"Women's group to bridge the gap" and "Include women's voices" "It just takes one" and "Uplifting women" and		
		10.4	"Unite their voices"		
	Need for involvement of women	"Consulting with people you provide service t "Give her skills to maintain her health"			
			"So we can have a voice"		
		6.24			
Understanding the system	Understanding of WCC	7.24	"Physical, mental, emotional health"		
	Ideal health centres	4.33	"Extra training that is trauma informed"		
		8.29	"Team approach" and "Take my kids" and "Connected"		
	Patient and women centred different	3.24	"Individualized" and "Not pushed through system"		
		4.23	"Trauma informed" vs. "Just physical being"		
	Not clear on difference between family and women care	5.14	"I guess"		
Role of Self- Identity	Age	2.3	"I'm young" and "I don't worry about it"		
	Work	1.22	"Run a women's group"		
	Class	1.6	"I couldn't afford a car"		
	Health	1.14	"Weekly injections"		
		2.31	"Disabilities and disorders" and "A huge stress"		
		8.14	"Gastric bypass" and "Never go away"		
	Understanding health needs	2.21	"Wish there were preventative measures"		
	-	9.18	"Put me at ease" and "Changed my approach"		

# APPENDIX O: Participant 3 Analysis Table



Superordinate themes	Sub themes	Transcript location	Identifier		
Dissatisfaction and Mistrust	Perceived weaknesses	1.14	"I do not go to her – better elsewhere"		
		4.4	"Didn't understand contraception" and "Stop getting paps"		
		4.31	"Lack sexual health information"		
		5.24	"Stop stigmatizing sexual health"		
	Feeling marginalized (self and others)	3.34	"I felt judged"		
		4.1	"Terrified for people who are not informed"		
		5.1	"Wait period for newcomers frustrating"		
		5.14	"Judgments" and "lack of knowledge for Queer identified"		
		5.33	"Women's health not a priority in Ontario"		
Perceptions of Care	Strengths of women's health centre	2.9	"Drop in access really helpful" and "Appointments much sooner"		
		3.34	"Pro-choice and support my decisions" and "No judgment"		
	Weaknesses of women's health centre	3.18	"Accessible if you have life of privilege"		
		4.4	"Fewer clinics than necessary"		
Navigating the system	Using multiple services	1.4	"University and clinic and another health clinic"		
Understanding the system	Ideal health centres	4.16	"Dropins, child care, pro-choice, sensitive to women's needs"		
	Women and family centred care different	2.29	"Pro-choice, well informed of reproductive rights" and "Just female"		
		3.1	"Family dynamic affecting their health"		
Role of Privilege and Self-Identity	Age	1.36	"Young and fit and healthy" and "Need regular access"		
<u>y</u>	Education and Work	1.2	"University degree"		
		1.32	"Fair amount of thought I place – I work at health centre myself"		
		5.4	"Studied medical anthropology"		
	Citizenship	2.2	"Without OHIP"		
	Health	1.35	"Anxiety and depression"		
	Identity	5.13	"As privileged as you can get. Caucasian, young, cisgendered"		
	Understanding health needs	5.5	"An academic perspective"		

#### APPENDIX P: Participant 4 Analysis Table



Superordinate themes	Sub themes	Transcript location	Identifier		
Dissatisfaction and Mistrust	Perceived weaknesses	2.7	"Interfered with the birth"		
		11.13	"Revolving door of young students"		
		11.29	"No continuity"		
		13.3	"Never go unless beaten to death" and "Appalling" and "Terrible"		
	No services	2.19	"Don't have a doctor"		
		11.1	"Haven't for 10 years"		
	Feeling marginalized	15.22	"Feel awful" and "Not listened to"		
		19.43	"I am marginalized"		
Seeking Alternatives	How she got there – through other services	13.21	"Sexual assault centre"		
Perceptions of Care	Strengths of women's health centre	2.31	"Background in psychology of health care made big difference"		
		12.34	"She was a genius, exceptional"		
		13.22	"Blown away by quality" and "What was happening emotionally"		
		16.23	"Really zeroed in on my self-esteem"		
		22.22	"I was kind of empowering to meet with her"		
		22.35	"Their woman focus" and "Take their time"		
	Weaknesses of women's health centre	16.33	"Not a good impression (of provider)"		
Role of Community	Relying on others	8.14	"Found a caring community with another single mom"		
Navigating the system	Inconsistencies between beliefs and actions	17.12	"Would never believe I wouldn't have a doctor"		
	Continuing to switch services	4.37	"Switched as well and it wasn't a good experience either"		
Role of Self- Identity	Age	1.18	"56"		
2	Relationship status and children	2.16	"Separated"		
	•	3.24	"Son showed signs of distress"		
	Class and Education	2.35	"Early childhood education"		
		3.32	"Struggling like crazy" and "Lift us out of poverty"		
		5.3	"Welfare"		
	Immigrant to Canada	1.14	"Liverpool"		
	Health	4.37	"Went to Prozac"		
		9.1	"Disability"		
		12.1	"Sexually assaulted"		
		22.22	"I'm health" and "I felt fragile"		

#### APPENDIX Q: Participant 5 Analysis Table



Superordinate themes	Sub themes	Transcript location	Identifier		
Dissatisfaction					
and Mistrust	Perceived weaknesses	1.18	"Not gender specific" and "Very dismissive"		
		2.28	"Didn't take me back" but "Husband still saw same doctor"		
		5.1	"Lost two doctors before we ever got to see them"		
	Feeling marginalized	9.12	"Broke all the rules" and "Didn't have any rights"		
Seeking Alternatives	Need for advocacy	9.26	"Have to be willing to right for it"		
Perceptions of Care	Strengths of women's health centre	3.18	"Women's health issues" and "Made it more comfortable"		
		4.4	"Prefer the nurse practitioner in most cases"		
	Weaknesses of women's health centre	3.7	"Could only go for women's health issues"		
		8.3	"I haven't received women centred care"		
Navigating the					
system	Using multiple services	2.1	"Two male doctors" and "Went to women's centre"		
Understanding the system	Understanding of WCC	4.31	"More than just anatomy but whole person" and "Mothering role"		
		10.3	"I had moved with an infant, with pneumonia and he came to see me"		
	Ideal services	10.8	"More smaller centres"		
		11.13	"Accessible" and "Families" and "Honouring" and "Community"		
	Family and women centred care different	6.23	"HUGE! Leaves out half of the women" and "For people who fit into that model" and "Would not want to see women's disappear"		
	Patient and women centred care different	7.34	"Trickery" and "Wash hands of responsibility"		
		8.9	"A misnomer" and "A different kind of model"		
Role of Self-					
Identity	Location	3.31	"Isolated"		
	Ethnicity	14.28	"First Nations"		
	Class and Education	3.11	"BSc in Nursing"		
		15.1	"Honours BA"		
	Health	1.14	"Radical reconstructive hysterectomy"		
		3.25	"Was really depressed"		
		10.37	"Asthma and allergies gone after stress gone"		

#### APPENDIX R: Participant 6 Analysis Table



Superordinate themes	Sub themes	Transcript location	Identifier
Dissatisfaction			"GP is an older male" and "Needed to convince
and Mistrust	Perceived weaknesses	4.12	him"
			"Prefer a referral after one visit" and
		4.25	"Uncomfortable with him"
	Feeling marginalized	4.2	"Downplay it" and "It wasn't a concern"
Seeking	How she got there – through friends		
Alternatives	and own needs	1.28	"Has a gym with aesthetic things"
		2.6	"The laser treatment I could actually find"
		6.11	"He saw a sign for it"
	Need for choice	8.21	"I wouldn't just settle"
Perceptions of			"A female doctor" and "Mostly male, I couldn't
Care	Strengths of women's health centre	1.5	relate"
		4.1	"Based on what I had before, it did represent my ideal"
	Changed understanding of health		"Made me think there are things I should be doing
	needs	12.1	and asking"
Navigating the	II. 1. 1	1 11	(WV)
system	Using multiple services	1.11	"Women's health centres in (two places)" "A lot of re-explaining of history but I came to
		2.21	expect that"
		6.22	"I've always gone back" and "Familiar"
Understanding			"Focus on what women would face" and "Different
the system	Understanding of WCC	2.17	from men"
		3.25	"Because the doctor was a female"
		10.8	"Wouldn't say it should be a priority"
		0.07	"Female and male oriented in one facility" and
	Ideal health centres	8.27	"Mental health"
	Family and women centred care different but not	3.3	"I think of children" and "Include a male"
		3.1	"I don't see a distinction"
Role of Self-		5.1	
Identity	Age	2.29	"More important as I get older"
		8.16	"Never crossed my mind before"
	Class and Education	1.2	"Finished my MA two years ago"
		11.13	"Social worker"
	Health	1.6	
		7.1	"Bladder issues"
			"Never had a health concern" and "Would think
		9.12	differently"

#### APPENDIX S: Participant 7 Analysis Table



Superordinate Categories	1	2	3	4	5	6	7
Women's health centres as an "alternatives" to other types of care	Dissatisfaction Seeking alternatives	Anger and mistrust Seeking alternatives	Dissatisfaction Seeking alternatives	Dissatisfaction and mistrust	Dissatisfaction and mistrust Seeking alternatives	Dissatisfaction and mistrust Seeking alternatives	Dissatisfaction and mistrust Seeking alternatives
Experiences at women's health centre	Perceptions of care	Perceptions of care	Perceptions of care Role of community	Perceptions of care	Perceptions of care Role of community	Perceptions of care	Perceptions of care
Understanding and navigating the system	Understanding the system Navigating the system	Understanding the system Navigating the system	Understanding the system	Navigating the system Understanding the system	Navigating the system	Navigating the system Understanding the system	Navigating the system Understanding the system
Understanding and contributions of "the self"	Role of self- identity	Role of self- identity	Role of self- identity	Role of privilege and self-identity	Role of self- identity	Role of self- identity	Role of self- identity

#### **APPENDIX T: Master Table of Superordinate Categories**



#### **VITA AUCTORIS**

Barat Jade Wolfe was born in 1981 in Cornwall, Ontario. She graduated from A.N. Myer Secondary School in 2000. She obtained a Bachelor of Science degree (with Honors) in Psychology from St. Lawrence University in 2004. In 2006, she earned a Master of Arts degree in Human Kinetics (Sport Psychology) from the University of Ottawa. She hopes to graduate from the University of Windsor with a Doctorate in Applied Social Psychology in 2012.

