# University of Windsor Scholarship at UWindsor

**Electronic Theses and Dissertations** 

Theses, Dissertations, and Major Papers

3-10-2021

# Dichotomies, Transcendence and Power: Investigating Women's Narratives of Breast Cancer Risks

Jane Elizabeth McArthur University of Windsor

Follow this and additional works at: https://scholar.uwindsor.ca/etd

### **Recommended Citation**

McArthur, Jane Elizabeth, "Dichotomies, Transcendence and Power: Investigating Women's Narratives of Breast Cancer Risks" (2021). *Electronic Theses and Dissertations*. 8567. https://scholar.uwindsor.ca/etd/8567

This online database contains the full-text of PhD dissertations and Masters' theses of University of Windsor students from 1954 forward. These documents are made available for personal study and research purposes only, in accordance with the Canadian Copyright Act and the Creative Commons license—CC BY-NC-ND (Attribution, Non-Commercial, No Derivative Works). Under this license, works must always be attributed to the copyright holder (original author), cannot be used for any commercial purposes, and may not be altered. Any other use would require the permission of the copyright holder. Students may inquire about withdrawing their dissertation and/or thesis from this database. For additional inquiries, please contact the repository administrator via email (scholarship@uwindsor.ca) or by telephone at 519-253-3000ext. 3208.

### **Dichotomies, Transcendence and Power:**

### **Investigating Women's Narratives of Breast Cancer Risks**

By

### Jane Elizabeth McArthur

A Dissertation

Submitted to the Faculty of Graduate Studies

through the Department of Sociology, Anthropology and Criminology

in Partial Fulfillment of the Requirements for

the Degree of Doctor of Philosophy

at the University of Windsor

Windsor, Ontario, Canada

2021

© 2021 Jane Elizabeth McArthur

**Dichotomies, Transcendence and Power:** 

**Investigating Women's Narratives of Breast Cancer Risks** 

by Jane Elizabeth McArthur

APPROVED BY:

P. Armstrong, External Examiner York University

> D. Rajacich Faculty of Nursing

G. George Department of Sociology, Anthropology and Criminology

J. Lewis Department of Sociology, Anthropology and Criminology

J. Ku, Advisor Department of Sociology, Anthropology and Criminology

February 2, 2021

### DECLARATION OF ORIGINALITY

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication.

I certify that, to the best of my knowledge, my thesis does not infringe upon anyone's copyright nor violate any proprietary rights and that any ideas, techniques, quotations, or any other material from the work of other people included in my thesis, published or otherwise, are fully acknowledged in accordance with the standard referencing practices. Furthermore, to the extent that I have included copyrighted material that surpasses the bounds of fair dealing within the meaning of the Canada Copyright Act, I certify that I have obtained a written permission from the copyright owner(s) to include such material(s) in my thesis and have included copies of such copyright clearances to my appendix.

I declare that this is a true copy of my thesis, including any final revisions, as approved by my thesis committee and the Graduate Studies office, and that this thesis has not been submitted for a higher degree to any other University or Institution.

iii

### ABSTRACT

Worldwide, almost 630,000 women died from breast cancer last year. North American women face a lifetime risk for breast cancer of one in eight, with nearly 500 new breast cancer diagnoses each week in Canada. The overall global incidence of breast cancer continues to rise. Five to ten % of cases are related to genetics, family history, lifestyle and behaviour, all factoring into overall incidence. Fewer than 50% of breast cancers can be explained by the known or traditionally suspected risk factors. The complexity of the varied contexts, which produce disparate degrees of risk, should be incorporated into prevention strategies. Increased attention to environmental and occupational risk factors represents a significant site where primary prevention interventions could be effective.

This qualitative study examines how women who work in an environment with an identified risk of breast cancer construct understandings and narratives of their risks and how women perceive and exercise agency in the acceptance, avoidance or negotiation of those risks. Personal narratives were gathered through in-depth individual interviews from 25 women who are current or former employees of the Ambassador Bridge in Windsor, Ontario, Canada. The research draws on Kleinman's ecological approach, where the subject location is key to the framework for understanding health information within its socio-cultural context. Kleinman's approach is further developed in this study by incorporating feminist standpoint theory and a socio-ecological framework. The theoretical approach constructed by incorporating these multiple perspectives frames women's subjective understandings as situated in their socio-cultural contexts and allows understanding subject location and, importantly, agency—or control over breast cancer risks—as seen through the subject in her location.

The narratives reveal how women construct their understanding of breast cancer risks, particularly concerning environmental factors, based on personal knowledge, occupational experience, and through the lens of gender. The exploration uncovers and analyzes how women's subject location influences understandings, interpretations and use of knowledge about perceived risks for breast cancer in a riskbearing environment and their related ideas about agency directed at risk mitigation. Policy, regulation, and risk mitigation strategies are enhanced by understanding how women make meaning in their knowledge of breast cancer risks and how they perceive the possibilities and barriers to agency to mitigate risks. The way women understand breast cancer risk is dynamic, contextualized, multisectoral, and relational and offers insights into understanding spaces. As seen from women's standpoint, breast cancer risk is not solely a biomedical phenomenon residing in the body, determined by genetics or lifestyle choices, but is experienced by women in a nested set of social, cultural and political relationships. Increased understanding and collaborative partnerships between medical science and social science would improve breast cancer prevention strategies, particularly where risks are related to involuntary, environmental exposures. The findings contribute to efforts to address environmental health risks at the Ambassador Bridge and other workplaces and communities.

### DEDICATION

To my children, Aelwynn and Eleanor: You are my reasons for everything.

To my family—my parents, my siblings and their families, and my late grandmother: You keep me grounded in what is important, and you remind me that I am part of that.

To all the women who participated in this study: You are brave and insightful, and I see your power. Thank you for giving your voices to this issue.

#### ACKNOWLEDGEMENTS

A special thanks to my dissertation committee: Dr. Jane Ku, Dr. Jacqueline Lewis, Dr. Dale Rajacich, Dr. Glynis George and Dr. Eleanor Maticka-Tyndale. Each one made significant contributions to this project and I am sincerely grateful. Thank you as well to my external examiner Dr. Pat Armstrong, and defense chair, Dr. Deborah Kane.

Thanks to faculty and staff: Dr. Janice Drakich, Dr. Nicholas Harney, Dr. Paul Datta, Dr. Gerald Cradock, Dr. Mark Munsterhjelm, Dr. Reza Nakhaie, Dr. Tanya Basok, Dr. Suzanne McMurphy, Dr. Gregory Feldman, Dr. Frances Cachon, Dr. Robert Arnold, Dr. Kathy M'closkey, Dr. James Winter, Dr. Victoria Paraschak, Dr. Charlene Senn, Dr. Karen Hobden, Dr. Jack Kapac, Donna Tourangeau, Kelly Element, and Dr. Patti Weir.

I am grateful to my UWindsor colleagues and dear friends: Dr. Amy Peirone, Dr. Allison Gray, Dr. Neil Porter, Dana Datta, Travis Reitsma, Renee Grozelle, Ayesha Mian Akram, Dr. Erwin Selimos. Also, to my friends in WOW (Windsor Essex on Watch) including the late Pat Noonan and Howard Pawley who inspired my work.

Sincere thanks to Kathy Mayville, Robert Earl Stewart, Helen Lynn, Dr. Michael Gilbertson, and Dr. Ana Porroche-Escudero for expertise, support and friendship.

I have been fortunate to receive many awards and scholarships: SSHRC Doctoral Fellowship, Gail Rosenblum Memorial Breast Cancer Research Scholarship, SSHRC Storytellers Final 5, Sociologists for Women in Society Barbara Rosenblum Cancer Dissertation Scholarship, Dr. R Whitehurst Graduate Scholarship, Elena Loaring Memorial Award for Breast Cancer Research, Graduate Student Society Scholarship, SSHRC-CRC Dr. Eleanor Maticka-Tyndale Scholarship, Ontario Graduate Scholarship, Centre for Research and Reasoning, Argumentation and Rhetoric Fellowship.

# TABLE OF CONTENTS

DECLARATION OF ORIGINALITY	iii
ABSTRACT	iv
DEDICATION	vi
ACKNOWLEDGEMENTS	vii
LIST OF FIGURES	xii
LIST OF APPENDICES	xiii
CHAPTER ONE	1
Introduction	1
Contextualizing the Problem of Breast Cancer	3
Central Questions and Aims of the Study	11
Significance of the Research	17
Outline of the Chapters	21
CHAPTER TWO	23
Theoretical and Analytical Approach	23
Locating Subject Knowledge	23
Figure 1: Kleinman's Approach to Health System Understandings	26
The cultural nestedness of information	26
Contemplating Agency	29
Points of Interaction in Health Understandings	
Moral Ordering of Risk Factors	
Contributions of Kleinman's Approach	
Adapting Kleinman's Approach to Understandings of Risk	34
Limitations of Kleinman's Model	
Expanding on Kleinman's Approach	
Incorporating Feminist Standpoint	36

Incorporating Structure Through the Lens of Agency	41
Narrative Analysis Through the Theoretical Lens	43
Theoretical and Analytical Approach Summarized	45
CHAPTER THREE	49
Analytical Framework for the Study of Breast Cancer Risk Narratives	49
Dominant Discourses and Representations of Breast Cancer: A Review of Literatur	e.49
Figure 2: An Adapted Illustration of Bronfenbrenner's Ecological Theory	50
The Concept of Risk	51
Behaviour Change	54
Discourses as Components of Narratives	58
Illness Narratives and Breast Cancer (Counter) Narratives	67
Feminist Perspectives	71
Locating the Environment in Breast Cancer Risk Perception	74
Integrating the Literature Towards the Study Objectives	77
CHAPTER FOUR	80
Research Design and Methodological Approach	80
The value of qualitative design for this research	80
Feminist Perspective Informing Methodological Approach	83
Methodology	85
Narrative Interviewing: Women as Authoritative Subjects	85
Narrative Analysis Through Theory	89
Discourse Analysis as a Component of Narrative Analysis	90
Study Context	91
Data Sources	92
Recruitment of Interview Sample	92
Sample Participants	93
Data Collection Procedures	94
Data Analysis	98
Figure 3: Theme, Category, Coding and Analysis Guide: The Research Questions .	101
Figure 4: Theme, Category, Coding and Analysis: Theme Identification	101

Figure 5: Theme, Category, Coding and Analysis Guide: The Interview Quest	ions102
Figure 6: Theme, Category, Coding and Analysis: Category Identification	
Figure 7: Theme, Category, Coding and Analysis: Category and Code Development	104
Figure 8: Narrative Analysis Framework: Health is a Nested Set of Relationsh	ips105
Figure 9: Theme, Category, Coding and Analysis: Tensions	106
Figure 10: Mapping the Generation of Themes, Categories, Codes	
Ethics	
Assumptions and Personal Stance	
CHAPTER FIVE	111
Narratives of Risk: Spaces Between Dichotomies	111
Understandings of Risks	112
Genetics and Heredity	114
Lifestyle and Life Course	
Incorporating Conditions of the Work Environment	
Sociocultural Systems of Risk: Disparities Between Discourses	
What Really Matters	141
Conclusions: Spaces between Dichotomies	144
CHAPTER SIX	
Narratives of Agency: Transcending the Implication of Individual Volition	150
Agency and Adaptive Tasks	151
Locating Agency in Women's Stories	
Personal Strategies	
Workplace Strategies	
Health System Strategies	
Structural Strategies	171
Agency Reflected through Moral Priorities	174
Conclusions: Transcending the Implication of Individual Volition	178
CHAPTER SEVEN	

Tensions, Conflict, Power, Resistance: Exposing the Paradox of Breast Cancer Control	184
Tensions and the Narratives of Resistance They Produce	186
Biomedicine	188
Suspicions	191
Economics	193
Gender	197
Harmony and Compliance	201
System Interactions	203
Difference and Power	207
Conclusions: Exposing the Paradox of Cancer Control	215
CHAPTER EIGHT	220
Discussion and Conclusions	220
Discussion	220
Key Findings of the Study	222
Insights and Analysis	225
Narrative Typologies in the Study	227
Figure 11: The Production of Breast Cancer Risk Narrative Typologies	228
Context	230
Conclusions	233
Contributions of the Study and Recommendations	233
Limitations, Strengths and Opportunities for Future Study	239
REFERENCES	243
APPENDICES	274
Appendix A: Interview Guide	274
Appendix B: Media Advisory	276
Appendix C: Study Flyer	278
Appendix D: Informed Consent	279
Appendix E: Interview Summary Template and Ongoing Consent	282
VITA AUCTORIS	284

# LIST OF FIGURES

Figure 1: Kleinman's Approach to Health System Understandings26
Figure 2: An Adapted Illustration of Bronfenbrenner's Ecological Theory50
Figure 3: Theme, Category, Coding and Analysis Guide: The Research Questions101
Figure 4: Theme, Category, Coding and Analysis: Theme Identification101
Figure 5: Theme, Category, Coding and Analysis Guide: The Interview Questions102
Figure 6: Theme, Category, Coding and Analysis: Category Identification103
Figure 7: Theme, Category, Coding and Analysis: Category and Code Development104
Figure 8: Narrative Analysis Framework: Health is a Nested Set of Relationships105
Figure 9: Theme, Category, Coding and Analysis: Tensions107
Figure 10: Mapping the Generation of Themes, Categories, Codes108
Figure 11: Narrative Typologies in the Study

# LIST OF APPENDICES

Appendix A: Interview Guide	279
Appendix B: Media Advisory	
Appendix C: Study Flyer	
Appendix D: Informed Consent	
Appendix E: Interview Summary Template and Ongoing Consent	

### **CHAPTER ONE**

### Introduction

In Windsor, Ontario, Canada, the Ambassador Bridge is a defining feature of the landscape. Spanning more than two kilometres, it connects two cities in two countries, bridging Canada and the U.S.A. across the Detroit River. It is now an important site for environmental health and justice. Growing up in Windsor, the Ambassador Bridge transported me over the river on numerous trips in my childhood to see the Detroit Tigers play baseball. The Bridge took me to the venue where I experienced my first big arena concert, mesmerized by the spectacle and Tina Turner's powerful voice. Our family crossed the bridge to make our way to Detroit's Metro Airport, our gateway to the southern states and warm spring breaks in a van packed with suitcases. In later years it marked the turnaround point in my long runs while training for the Detroit Free Press Marathon—a race that would see me cross the bridge into Windsor with thousands of other runners competing in the world's only international marathon. I later came to understand its significance in global trade and politics, especially in the wake of 9/11, when crossing the border took on new significance under heightened security and increased restrictions. Furthermore, through my involvement in a network of researchers studying occupation and breast cancer, I also became aware of an alleged cluster of breast cancers among women working at the Ambassador Bridge, which lead to an altered perception of the bridge, and what it means in the communities it connects and serves.

My earlier personal experiences with the Ambassador Bridge as an exciting crossing overshadowed the lives of women who worked there, took our bridge tolls, stamped our receipts, and watched over our border while facing the environmental risks of breast cancer. Mostly unheard, their stories have become the new landscape of the Ambassador Bridge for me as an environmental health researcher and advocate.

The personal stories of the women who work at the Ambassador Bridge illuminate the complexity of the experience of breast cancer risks, including environmental risks. As a disease experienced predominantly by women, breast cancer is a serious international public health issue that requires further study. Breast cancer has been conceptualized principally within a misconstrued framework of public health as an individualized problem. This framing excludes the role of environmental and occupational risk factors. The most frequently promoted cancer control strategies follow in that framework. However, there are deeply entrenched institutional causes of breast cancer that limit the effectiveness of the individually focused framework of public health. Social context and contributors to risk beyond genetics and behaviours cannot be ignored in breast cancer prevention efforts.

Occupational and environmental breast cancer prevention is a political, social and economic issue. Confronting the contentious problem of breast cancer risk necessitates apprehending the socio-ecological context, including the ideological influence of neoliberalism and its limitations on effective strategies for the primary prevention of breast cancer. The stories of the women who work there constitute a new understanding of the Ambassador Bridge. Their stories are a symbolic bridge to cross in efforts to understand the social contexts that contribute to breast cancer risks and that comprise barriers to breast cancer prevention efforts.

### **Contextualizing the Problem of Breast Cancer**

Fourteen Canadian women die each day from breast cancer. North American women face a lifetime risk for breast cancer of one in eight, with almost 500 new breast cancer diagnoses each week in Canada (cancer.ca, 2019). Incidence is rising in younger women, specifically in premenopausal women (Canadian Cancer Society, 2019; SEER, 2019). Worldwide, almost 630,000 women died from breast cancer last year (World Health Organization, 2019). The overall global incidence of breast cancer continues to rise with marginal improvements in the last few decades in terms of five-year survival rates (SEER, 2019). Five to ten percent of cases are related to genetics, family history, lifestyle and behaviour, all factoring into overall incidence. Fewer than 50% of breast cancers can be explained by the known or traditionally suspected risk factors. The complexity of the varied contexts which produce disparate degrees of risk should be incorporated into prevention strategies. Factors such as gender, social class, ethnicity, migration status, geographic location, environment, and occupation also contribute to inequalities in risk (Gray 2010; Breast Cancer Fund, 2016). Increased attention to environmental and occupational risk factors represents a significant site where primary prevention interventions could be effective.

Understood as "the surroundings or conditions in which a person, animal, or plant lives or operates; the setting or conditions in which a particular activity is carried on; the natural world, as a whole or in a particular geographical area, especially as affected by human activity" (oed.com, 2019), a person's environment includes the many social elements in which they live and work. Exposure to multiple anthropogenic<sup>1</sup> pollutants is associated with adverse human health impacts, including thyroid diseases, birth anomalies, asthma, autism, cardiovascular disease, and cancers inclusive of breast cancer (The Collaborative on Health and the Environment, 2019; World Health Organization, 2018). Recent studies suggest the contribution of extrinsic—or environmental—factors for breast cancer development are present in 70-90% of cases (Luginaah, Gorey, Oiamo, Tang, Holowaty, Hamm & Wright, 2012; Torre, Islami, Siegel, Ward & Jemal, 2017; World Health Organization, 2019). Research shows a disproportionate burden of ill health, including breast cancer, among populations who reside or work in elevated exposure pathways (Chen et al., 2008; Luginaah et al., 2012; Villeneuve et al., 2018; Engel, Rasanaygam, Gray & Rizzo, 2018).

Increasingly, indoor and outdoor air pollution is considered the most important environmental health risk worldwide and is associated with breast cancer (Dias, 2018). Increased levels of pollution in workplace environments due to high volumes of traffic and industrial activity (Gilbertson & Brophy, 2001; Gilbertson & Brophy, 2018; Morello-Frosch et al., 2011) may be related to a category of chemicals known as endocrine disruptors, commonly found in industrial and transportation-related pollutants (Brophy et al., 2012; Crouse, Peters, Hystad, Brook, van Donkelaar & Martin, 2012; Gray et al., 2017; Hystad, Demers, Johnson, Carpiano & Brauer, 2014; Mordukhovich et al., 2016; Pan et al., 2011; Rudel & Perovich, 2009; Schettler, 2014). Higher levels of exposure to fine particulate matter (PM2.5)<sup>2</sup> is increasingly found to be in correlation with increased breast density—an established breast cancer risk

<sup>&</sup>lt;sup>1</sup> Anthropogenic is the term used to denote human-originating activities or effects

<sup>&</sup>lt;sup>2</sup> PM2.5 refers to atmospheric fine particulate matter that are 2.5 microns or less in diameter

factor. Numerous studies demonstrate that timing of these exposures at specific windows of vulnerability along the life-course, as well as combinations of exposures, are also critical in the development of breast cancer (Engel, Rasanayagam, Gray & Rizzo, 2018; Gray, Rasanayagam, Engel & Rizzo, 2017; Schettler, 2014; Wu et al., 2016). This phenomenon points to the importance of more in-depth examination of the contexts of these exogenous exposures, including air pollution (Gray, Evans, Taylor, Rizzo & Walker, 2009; Gomez et al., 2010; Nudelman et al., 2009; Engel, Rasanaygam, Gray & Rizzo, 2018; Pederson et al. 2020; Niehoff et al., 2020).

The complexities of risk factors for breast cancer include "changes in reproductive factors (e.g., higher age at first live birth, lower breastfeeding rates, earlier onset of menstruation) and lifestyle factors (e.g., diet) but could also indicate variations in other environmental exposures" (Gomez, Quach, Horn-Ross, Pham, Cockburn, Chang, Keegan, Glaser & Clarke, 2010, p. 1). Breast cancer rates among women who migrate to more industrialized countries—where endocrine-disrupting chemicals are ubiquitous and hard to ignore as risk factors (Yaghjyan et al., 2017) tend to rise within a generation of living in the host country. A further complication of gaps in knowledge of risk factors stems from American research as Canada does not systematically collect data on race and ethnicity for breast cancer (Grant & Balkissoon, 2019). A greater understanding of the presence and impacts of the many factors in addition to lifestyle and genetics that contribute to breast cancer risk is necessary to understand causation and enact effective prevention strategies truly.

Biologist Rachel Carson, considered one of the earliest and most important influences on the modern environmental movement, sounded an early warning on the possible association between cancer development and environmental exposures in her classic 1962 book *Silent Spring*. Following her footsteps, recent activities underscore the importance of the role of the environment in breast cancer. Among the progress in advancing the issue is: research identifying exposures in the workplace and in the general environment that may be contributing to breast cancer (Rodgers, Udesky, Rudel, Brody, 2018); community campaigns addressing the challenge of public recognition of these risk factors (cwhn.ca; acsqc.ca; bcpp.org; bcaction.org); films and books confronting the controversies associated with the disease including fundraising initiatives, research priorities and more (Batt, 1994; King, 2008; Pool, 2011; Levine, 2012, Nielsen, 2018); academic work acknowledging the social disparities that make this a complicated puzzle (White, Peipins, Watson, Trivers, Holman, Rodriguez, 2013; Gray, 2017); the American Public Health Association's Policy Statement on Breast Cancer and Occupation issued in 2015; and global networks of researchers, academics, scientists, advocates, activists and others working towards a greater understanding of environmental and occupational links to breast cancer

(allianceforcancerprevention.org). These efforts are essential to understanding the complexity of social conditions related to breast cancer prevention.

A search of the University of Windsor Leddy Library Primo Exlibris database for the terms "breast cancer" and "environment" returns more than 110,000 peerreviewed publications (the process of de-duplication occurs within the database), suggesting interest and knowledge in this area is considerable. In addition to research collaboratives dedicated to this specific research area, including the U.S. National Institute of Environmental Health Sciences and the Breast Cancer and Environment Program lists over 240 publications since 2004. Silent Spring Institute, which takes its name from Carson's book, is a partnership of scientists, physicians, and public health professionals. They have advocated for investigating environmental links to breast cancer since 1996, and its members have published 127 articles in peer-reviewed journals, 13 study reports, 75 conference abstracts, and 23 collaborator peer-reviewed publications. These are but a few examples of the ongoing work in this area (silentspring.org).

While breast cancer causality is, without a doubt, a complex science, there is a substantial and growing body of evidence that points to questions about environmental factors associated with the development of breast cancer. Researchers argue that continued research in this area is necessary.

As the genomic changes that lead to cancer have become better understood, so too has the importance of the interaction between genes and the environment in cancer development... Applying what we learn about gene-environment interactions to preventive interventions highlights an important distinction between individual and population-based strategies for prevention. (White et al., 2013, p. 3)

Despite the evidence of environmental contribution to breast cancer risk, predominant constructions in medical and mainstream discourses centre on lifestyle factors and personal responsibility (Brophy, Keith, Watterson, Gilbertson & Beck, 2012; Brophy et al., 2012; Brown et al., 2006; Gray, Rasanayagam, Engel & Rizzo, 2017; Lupton, 1994; McArthur, 2014; Schettler, 2014; Sweeney, 2014). Studies on women working in industries with elevated breast cancer risks, women's health and environmental

organizations, labour unions, breast cancer advocacy groups and academics conclude that environmental risk factors remain poorly understood by women ("Prioritizing Breast Cancer Prevention," 2013). Gaps in research, communications, knowledge and awareness are all part of the social context of breast cancer that contributes to the failing approach to breast cancer prevention and bring to the forefront that interventions beyond the scope of individual agency, as is the case with environmental and occupational exposures require other actions strategies.

Breast cancer is a social problem where history and biography collide. As a researcher and environmental health advocate, my perspective on breast cancer has changed: where the Ambassador Bridge was once emblematic of an entrée to recreational pleasures, I now see it as signifying the lives of women and their breast cancer stories. Following C. Wright Mills' perspective on the "sociological imagination" as the concept through which the interconnectedness of self and society are understood (Mills, 1959), breast cancer is not just a personal issue. It is also a societal issue. Unfortunately, breast cancer's traditional, popular narratives are focused principally on the individual instead of populations situated in their social contexts. These narratives disregard public health principles of emphasizing a collective epidemiological approach focused on prevention. In 1854, Dr. John Snow went against the then conventional view that cholera was spread in the air and instead recommended removing the Broad Street water pump's handle to stem the epidemic of cholera in England. The removal halted the spread through contaminated drinking water (although he was unaware of specific pathogens' existence or role), leading to a dramatic drop in new cholera cases. This story highlights the origins of public health

and epidemiology. Snow's population-based, prevention-oriented strategy seems relegated mainly to the past, replaced by the neoliberal approach of focusing on individual lifestyle factors.

Neoliberal ideology, a seemingly defining feature of the present era, influences the social context in important ways. It ascribes responsibility for many aspects of life, including health and illness, to the individual level and away from collective, structural and systemic explanations. At the same time, neoliberal discourses omit the socio-political factors and politics influencing public issues. The individualized approach largely omits the social context of health and illness, including occupationally and environmentally related breast cancer. "The scientific impasse regarding the avoidable causes of cancer exists within a social, political and economic context that promotes the notion of individual behaviour as the primary aetiologic factor" (Brophy & Keith, 2011). It is a central tenet of this research that individuals largely lack control over their environments—including occupational environments—and the responsibility for mitigating breast cancer risks cannot be placed on individual women.

The socio-ecological context of breast cancer is key to understanding the dominant narratives' influence, and to my analysis of the 25 women's narratives as deeply intertwined with their social locations. Schettler argues that breast cancer "is not only a disease of abnormal cells but also of communities that we create and live in" (Schettler, 2014, p. 4). I apply an ecological framework to capture the multiple levels of interactions and relationships that influence the health of individuals and

populations, and in particular, breast cancer in relation to the social and spatial context—environmental breast cancer.

While there is substantial and growing scientific evidence of cancer risks associated with particular occupational and environmental exposures, breast cancer, like cancer in general, is primarily viewed as a disease of individual lifestyle or bad luck and thus largely modifiable; its cause by exogenous factors is still contested (Brown, 2007). "What is remarkable about the long history of focus on modifiable risk factors such as lifestyle and diet," wrote Rochon, Ford and Sweeney in their 2015 study "is that the official narrative rarely concedes that these factors account for only a fraction of breast cancer incidence" (Rochon Ford & Sweeney, 2015, p. 295). Instead of asking women to modify their behaviour, uncovering the value in women's stories to find alternative ways of preventing breast cancer is foundational to my exploration.

My communications background brought me to attend to *what* and *how* information is shared, received, and incorporated. The lack of attention to environmental risks for breast cancer and related primary prevention messages is a glaring omission of vital information. It was essential in the context of my research to investigate what women knew about these issues, how they knew it, and what they thought should be done, if anything, when it came to breast cancer risks. Thus, my research interest arose from my communication studies experience, health promotion and research, and commitment to improving women and their communities' health. The Ambassador Bridge, given its geographic, environmental, and occupational specificities, is an apt location to explore women's knowledge of breast cancer risks

10

and how they narrate their experiences concerning conventional emphasis on individual behaviour change and choices as the primary mode of prevention.

### **Central Questions and Aims of the Study**

This dissertation examines how women who work in an environment with an identified risk of breast cancer construct understandings and narratives of their risks and how women perceive and exercise agency in the acceptance, avoidance or negotiation of those risks. I build on my academic and advocacy interests and concerns and problematize the individualist approach with an ecological approach to cancer prevention as the impetus for this study. I am also concerned with how the subject of environmental risk is introduced and assessed within the overall breast cancer risk information framework women can access.

The thesis exploration includes sources of information, availability of information, interpretations of information, and the grounding of the interpretations of breast cancer risk information in subject<sup>3</sup>, location and experience. Whether the messages about breast cancer causality and prevention come from mainstream media, internet sources, family, friends, doctors, co-workers, or personal experiences, they meaningfully influence how women conceive of and frame the issue. The narrowness of the discourse is intricately connected with policy, regulation, legislation, compensation, medical and health care, and society's ruling relations. With a greater understanding of the relationships between information, discourse, understanding of risk, and breast cancer risk mitigation strategies, breast cancer prevention activities

<sup>&</sup>lt;sup>3</sup> The use of the word "subject" here and throughout is used in reference to location and as a concept in and of itself, namely "subject location". The term subject as it is used in the dissertation is not used to signify the actual interview participants in this study, but rather as a signifier for situatedness of subjects generally.

could be more comprehensive and effective. Finally, the women's experience at the bridge compels me to begin with their narratives; to incorporate their meanings and understanding about cancer risks in the continuing production of environmental breast cancer knowledge.

The central questions of the research are:

- How do women who work (or have worked) in an environment identified as posing an increased risk of breast cancer construct narratives and understandings of their breast cancer risks?
- 2) How do women place the environment in their narratives?
- 3) How do these women perceive and exercise agency in the context of those risks?

The research aims to develop an understanding of how the multiplicity of breast cancer risks are constructed and understood by women and how women respond to and enact agency in response to breast cancer risks. What information women include on identified risk factors for cancer, in addition to their lived experiences as women, and other intersectional factors, are central to this investigation. In the context of the Ambassador Bridge environment, whether and how information about air pollution, vehicle exhaust, exposure to radiation, shift work, and second-hand tobacco smoke—all factors identified in the scientific literature as associated with an elevated risk for breast cancer—is understood by the women is particularly illustrative of occupational exposures associated with the disease. As well, how women respond to the question of who has control over risks for breast cancer is especially indicative of agency (or actions) identified as facilitating breast cancer risk mitigation. Agency, in this case, comprises the scope of actions beginning with individual action to action directed at structures and governance.

The typically narrow, biomedical discourses and gaps in knowledge and information on risks related to media environments and other formal mediums are an important component of the context that reinforces inadequate policy, regulation, and legislation. It is therefore of crucial importance to understand what information about breast cancer risks is disseminated, and how that information is interpreted and incorporated into women's understandings. Also important is how women resist the dominant discourses of breast cancer risk while drawing on alternative sets of knowledge (including their own experiences), and how this knowledge can be applied toward improved policy, regulation, legislation, and health care.

The research draws on Kleinman's ecological approach outlined in his paper "Concepts and a model for the comparison of medical systems as cultural systems" (1978)<sup>4</sup> as a starting point. The subject location is key to Kleinman's framework for understanding health information within its socio-cultural context and through subject narratives. Situating the subject as central to the analysis foregrounds women's perspectives. This approach facilitates the illustration of how women perceive appropriate strategies for action as understood within the workplace or locus of exposure to breast cancer risk factors, and how and why they construct specific breast cancer risk mitigation strategies. Kleinman's approach also describes subjects' use of

<sup>&</sup>lt;sup>4</sup> Kleinman's paper describes his development of a model. The model is referenced here as part of an overall approach taken by Kleinman and adapted in this research as an approach to situating medical patients or subjects in their cultural location. For the purposes of this research, in the dissertation, Kleinman's model will be referred to and applied predominantly as an approach, and not as something to guide strict adherence to.

"moral ordering" of information within narratives based on "what really matters" (2007) to them. According to Kleinman (1997, 2007), *what really matters* are 'moral decisions' made in the face of danger and uncertainty and are reflections of context, experience, and subjective importance, influencing the construction of priorities. Among these priorities may be status, jobs, money, family, sexuality, order and control, health, life, religious commitments, political arrangements, "and all sorts of culturally and personally specific agendas" (Kleinman, 2007, p. 6).

Kleinman's approach is further developed in this study by incorporating feminist standpoint theory (Smith, 1979, 1997) and a socio-ecological framework (Bronfenbrenner, 1977; Schettler, 2015; CHE, 2020). Feminist standpoint theory nested in a socio-ecological frame enhances Kleinman's approach of situating the subject and further develops the idea of 'what really matters' to apprehend the influences on their priorities and understandings. The theoretical approach constructed by incorporating these multiple perspectives frames women's subjective understandings as situated in their socio-cultural contexts. Furthermore, the broadened theoretical approach allows for an understanding of subject location and, importantly, agency—or control over breast cancer risks—as seen through the subject in her location.

The research for this dissertation uses a qualitative study design focused on the personal narratives of 25 women. Gathering and analyzing women's narratives is the central method for this research. The narratives herein are the stories women tell of their understandings of breast cancer risks. These stories reveal how the women construct their understanding of breast cancer risks, particularly concerning

environmental factors, based on their personal knowledge, employment-based experience, and through the lens of gender and other intersectional factors. The exploration of how these women make sense of their breast cancer risks provides an opening for elaborating cultural contexts and the role of agency. By gathering and analyzing personal narratives of women in an environment with identified risks for breast cancer, the study aims to uncover and provide analysis of how women's subject location influences their understandings, interpretations and use of knowledge about perceived risks for breast cancer in a risk-bearing environment, and their related ideas about agency directed at risk mitigation.

The 25 narratives analyzed for this research are women who are current or former employees of the Ambassador Bridge in Windsor, Ontario. Connecting Windsor, Ontario, Canada, with Detroit, Michigan, U.S.A., the Ambassador Bridge is the busiest border crossing in North America, with over 20,000 transport trucks and other vehicles crossing each day. As a result, there is heavy traffic pollution. The bridge is located close to numerous industrial steel and automobile manufacturing operations, thereby adding to the mix of pollutants in the bridge environment.

At the time of this research, the Ambassador Bridge was privately owned by multi-billionaire American businessman Manuel "Matty" Moroun (LeDuff, 2018). Operations at the Ambassador Bridge comprise a significant Canada-U.S. trade component, with \$500 million per day crossing the international span. Canadian Border Services Agency (CBSA), an agency of the Canadian Federal Government, employs the approximately 540 border guards and clerical staff who are unionized with the Customs and Immigration Union (CIU), part of the Public Service Alliance of Canada (PSAC) (CTV, 2018). CBSA hiring practices have seen an increasing number of women employed at the Bridge; women now make up a little over half of the workforce. The Detroit International Bridge Company referred to as the Ambassador Bridge Company and the Ammex Duty-Free Stores, all privately owned, employ traffic control, maintenance, and retail workers at the Bridge. The Bridge Company and Duty-Free Stores also employ women, including young women, for co-operative and seasonal employment.

The Ambassador Bridge is an environment with identified exogenous exposures associated with an elevated risk for breast cancer (Brophy et al., 2012; Crouse et al., 2010; Gray et al., 2017; Hystad et al., 2014; Mordukhovich et al., 2016; Pan et al., 2011; Schettler, 2014; Wu, Powers, Zhu & Hannun, 2015). Reports show that nitrogen oxide (NO<sub>2</sub>) levels in this area are ten times higher than most Canadian urban environments (Crouse et al., 2015), with multiple studies identifying adverse health consequences associated with these pollutants (Atari & Luginaah, 2009; Crouse et al., 2012; Gilbertson & Brophy, 2018; Luginaah et al., 2006; Luginaah et al., 2011, Lougheed, 2014; Villeneuve et al., 2018). Widespread dominant constructions of breast cancer risk in medical, epidemiological and media frameworks focus on lifestyle factors, genetic factors, and personal responsibility (Brophy et al., 2012; Brown et al., 2006; Gray et al., 2017; Lupton, 1994; McArthur, 2013; Schettler, 2014). Because of their exposures, multiple identified environmental risks, and reports of a cluster of breast cancers among the workers there, the women working at the bridge bring unique perspectives to their risk constructions as rooted in their experiential

knowledge. The bridge workers offer a broader range of discourses than the discourses that prevail in the dominant constructions of breast cancer risk.

### Significance of the Research

This research contributes to knowledge about women's understanding of breast cancer, how women assess risks for breast cancer in their own lives and others' lives, and how they make corresponding decisions about mitigating those risks. The research also contributes to developing a nuanced understanding of how the multiplicity of breast cancer risks are constructed, understood and responded to by women exposed to environmental and occupational risks for breast cancer. Furthermore, women's insights about breast cancer risk controls contribute to targeted risk mitigation strategies, mainly where occupational and environmental exposures are concerned. Not only is this an understudied area in social science research, but the production of mitigation strategies for environmental exposures is essential given the increases in breast cancer incidence in populations at risk.

The importance of understanding the environmental risk factors is spelled out in the position of the U.S. Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERC). Their research indicated that environmental factors for breast cancer are "more readily identified and modified than genetic factors and therefore present a tremendous opportunity to prevent breast cancer" (IBCERC, 2013). The IBCERC identifies an opportunity for prevention as achievable through their recommendations for: increased prevention efforts, continued research on chemical and physical agents found in the environment, making scientific knowledge accessible to the public, and addressing vulnerable populations such as women in high prevalence or high-risk occupational groups (IBCERC, 2013). The women at the Ambassador Bridge are one such group, and therefore, researching their understandings and related risk-mitigation strategies for environmental breast cancer can facilitate the achievement of the IBCERC perspective.

Another significant contribution of this research is its elucidation of how narratives of health risk are constructed. Following in the theoretical framework that roots women in their social locations, these narratives illuminate how understandings of scientific, medical, or epidemiological evidence are incorporated into risk narratives. These narratives also illustrate how biomedical evidence is combined with socio-cultural and biographical information in the overall narrative. Using a lens that situates women in their subject location, their health narratives can be analyzed as expressions of the cultural system. The intersection of different and sometimes conflicting information sectors is incorporated and made meaningful in constructing the narrative. In a socio-cultural climate where there is increasing recognition of the effects of the environment on health, whether and how multiple risk factors for health are incorporated into these narratives is essential for effective future health communication and health-enhancing strategies.

In addition, this study contributes to theory development. Given the inductive nature of the project—taking what is found in the risk narratives and using this information towards developing theories about what is discovered—this research adds to Kleinman's theoretical concept, contributing importantly to an understanding of what really matters. The approach's enhancement extends its key feature of prioritizing subject location, incorporating feminist standpoint theory, and a socio-ecological

framework. These aspects of health understandings are important contributions to the social science knowledge of environmental breast cancer risks.

Remaining open to what the lens of lay-knowledge contributes to our health understandings allows us to see how the narratives collected and analyzed in this research provide nuanced explanations of those understandings of environmental causes of ill health, including inequalities. Professor of Sociology and Public Health, Jennie Popay, and colleagues posit that in the theorizing of health inequalities, lay knowledge plays the role of "mediating the relationship between structural inequalities, individual or group action and health status" (Popay, Williams, Thomas & Gatrell, 1998, p. 621). Incorporated into women's narratives, this lay knowledge generates insights and evidence of an ontological status that contributes to new ways to understand environmental breast cancer risk through different knowledge categories. Furthermore, women's breast cancer risk narratives can capture social processes and the complexities of relationships between individuals, social action, and macro-level societal organization. In this way, counter-narratives-or narratives that challenge or resist dominant socio-cultural narratives—may be produced by the women as they grapple with their subject location's specificities while accounting for influences from the micro to the macro levels of their social location and relationships.

Understanding how women construct narratives on breast cancer risks and how they incorporate environmental risks in their narratives can contribute to future prevention policy and regulatory revisions. Women's narratives of breast cancer risk and risk mitigation strategies may lend critical knowledge and information to changes pursued at the local level, such as prohibiting vehicle engine idling. At the regulatory policy level, they may also lead to the lowering of allowable limits of exposures to risk in occupational and environmental settings and actions leading to revising worker compensation policy. Health communications can be meaningfully influenced through a shift in breast cancer's dominant discourses to include involuntary exposures in environments. By extension, more widespread national and even global cancer control strategies may begin to target structural and systemic contributions to breast cancer risks that individual agency is incapable of targeting. These understandings can, importantly, inform improvements aimed at the primary prevention of breast cancer.

Finally, in keeping with the roots of public health, which are population-based, prevention-oriented, and which look at the public collectively in contrast with the neoliberal tendency of individualizing social problems (Bhuyan, Jeyapal, Ku, Sakamoto & Chou, 2015), this research contributes to the arguments for the reclaiming of the broader societal view of health as wholeness. Through this research's unique theoretical framing, narrative inquiry and analysis take social context into account, and so should public health policy and initiatives. A systems model of health, where an ecological perspective is utilized, is beneficial not only in understanding narrative construction but also in creating healthier communities.

As seen through this study, the women's stories at the Ambassador Bridge emphasize important lessons in the roots of public health. Policy, regulation, and risk mitigation strategies can all be enhanced through a deeper understanding of how women make meaning in their knowledge of breast cancer risks, and how they perceive their agency—the pathways and the barriers—to mitigate those risks. Women's narratives of breast cancer risk can contribute to efforts to address environmental health risks not only at the Ambassador Bridge, but in other workplaces and communities across the globe.

### **Outline of the Chapters**

This dissertation is organized into eight chapters. Following this introductory chapter, Chapter Two outlines the theoretical perspectives that influenced and informed the study, elucidating the unique approach used that incorporates Kleinman's concepts and feminist standpoint theory, both grounded in a socio-ecological framework. Chapter Three locates the study in the literature relevant to an investigation of health narratives and understanding and outlines the dominant discourses and representations of breast cancer, and places these within the corpus of sociological work on health risks. Chapter Four presents the study methodology, outlining the qualitative research design steps for the project, beginning with a description of the study context. Chapter Five is the first of the three analytical chapters on the critical themes identified in the narratives, beginning with risk narratives. Chapter Six addresses agency, through the analysis of how agency is conceptualized in actions towards risk mitigation, is constructed by the women in their narratives. Chapter Seven addresses tensions, conflicts, and power identified in the narratives as particularly conspicuous aspects of the themes that emerged. These subjects present a specific narrative type—one of resistance to the more socially dominant breast cancer narratives. Chapter Eight begins with a discussion of theoretical insights drawn from the narratives' analysis and then contextualizes them. Key findings are presented in the form of conclusions and synthesis. Context and contributions of the study are addressed, including some of the potential implications

of the findings. Finally, the limitations and strengths of the study and opportunities for future research are presented.

## **CHAPTER TWO**

## **Theoretical and Analytical Approach**

### Locating Subject Knowledge

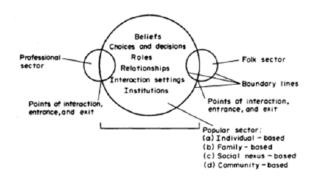
Two significant factors problematize the issue of environmental breast cancer risk. First, the limitations of the biomedical model of health that fundamentally focuses solely on individual biology while excluding social, political and environmental factors related to health. Second, the tendency to individualize health responsibilities while seeing the individual body as separate from the socio-ecological contexts that impact health and beyond the scope of individual control. The individualized approach to health includes neoliberal and corporate discourses espoused in breast cancer risk representations. To capture these specificities of breast cancer risk discourses, in particular the environmental (or exogenous and involuntary) contributions to risk as they are understood by women, an approach to narrative analysis that foregrounds the subject in their location was chosen for this study.

The study uses Arthur Kleinman's paper "Concepts and a model for comparison of medical systems as cultural systems" (1978) as its theoretical starting point. Kleinman, a psychiatrist and medical anthropologist, researched data from numerous countries and developed his concepts and model for capturing the cultural specificities that influence patient experience and treatment choices. Based on his empirical studies, field research experience, his reading of relevant theories and concepts used to compare medical systems as cultural systems, and his understanding of how health systems are different across cultures and contexts, Kleinman developed an approach that situated subjects' health understandings and choices in their cultural locations (Kleinman, 1978, p. 85).

Published in 1978, the paper was a product of Kleinman's efforts to reconcile science and medicine with culture. He recognized that patients exercised agency in decision making about their illnesses and did not necessarily accept medical advice from physicians or other medical practitioners. Kleinman's research illustrated that patients and families might incorporate knowledge from their physicians, but they may also draw on popular and folk knowledge when making choices about understanding and treating their illnesses. The fundamental observation he makes is that patient agency is exercised within a framework of the medical system *as a cultural system* where medical knowledge is just one aspect of a broader system of information sources and cultural influences that determine the decisions and actions patients make in the face of illness. Kleinman's approach is ecological, situating the subject in their context where illness understandings and treatment decisions are constructed by the subject using the intersection of several cultural and personal influences.

The locus of the subject and related agency as situationally specific in Kleinman's framework is key to applying it as a starting point for this study. Also important is Kleinman's definition of culture as "a system of symbolic meanings that shapes both social reality and personal experience, [and] mediates between the "external" and "internal" parameters of medical systems" (Kleinman, 1978, p. 86). Given the traditional discourses and biomedical representations of breast cancer risk that foreground individual responsibility and behaviour, understanding the role of cultural process in the construction of risk narratives is key to appreciating how women accept, problematize, and resist dominant cultural meanings related to breast cancer. By situating the subject and recognizing their agency within cultural systems comprised of multiple sectors, including the medical system, Kleinman's approach recognizes that actors incorporate different knowledge spheres to construct health understandings, drawing on knowledge grounded in their nested set of relationships and socio-cultural influences.

Kleinman's approach defines three interrelating information sectors—popular, professional and folk—to illustrate how social and cultural factors come to bear on understandings and experiences of health and illuminates how particular domains may be privileged over others in the construction of health narratives. The professional sector comprises medical, biomedical, scientific, technical, and other "expert" sources. The folk sector includes spiritual and alternative knowledge, indigenous folk healers, social workers, psychiatrists, pastors and patient advocates. The popular sector is comprised of individual, family, social nexus and community-based activities. Each of the information sectors is influenced by beliefs, choices, decisions, roles, relationships, interaction settings and institutions. As incorporated into illness experiences and health understandings, the interplay and relationship between the sectors and the other interaction points is illustrated in Kleinman's approach (see Figure 1).



The graphic depiction of Kleinman's approach illustrates how health-related narratives are constructed as situated in their cultural context, incorporating varying sources of information from different sectors – namely Professional, Popular and Folk – through a process of prioritizing and making decisions about the various sources of information (Kleinman, 1978, p. 86).

## Figure 1: Kleinman's Approach to Health System Understandings

# The cultural nestedness of information

Kleinman asserts that popular knowledge is central in the creation of "socially meaningful explanations" (Kleinman, 1978, p.89) and estimates that 70-90% of the management of health understandings is grounded in the popular sector (1978, p.86). It is important to note that information mobilization has evolved and changed with technology, particularly with the introduction and dominance of internet-based information in the popular sector, which Kleinman's approach pre-dates. In the present, where internet-based information is part of the popular cultural context, how women incorporate and assess information from various sources, including the internet, is an important dimension to consider in analyzing health narratives. It is an especially vital consideration given that the popular sector, as Kleinman points out, is a significant information source in constructing social reality (Kleinman, 1978, p. 87).

Whereas professional associations and access to professionals (e.g., Health Canada, Ontario Medical Association) may have been limited in the past, the claimed democratization of access to information via the internet has changed so that information is available outside of traditional networks making accessibility of the information sources popular. The internet includes sources that may, by definition, fall under any one of the three information sectors defined in Kleinman's approach. Sorting out which source is professional, which is popular, and which is folk knowledge is a further complication for users interpreting the credibility of the information. As such, internet-based information contributes to the complications of the interrelationship and conflicts between multiple sectors in constructing the experience and understandings of breast cancer risk. Media literacy, specifically verifying sources and the authenticity and credibility of the information and their sources and influences, is a sub-concern of this that would warrant greater discussion than is possible here.

Tensions between sources of information and transposition of these tensions to understandings through lived experience reveal how meaning is made, and how sensemaking occurs. The tensions become particularly pertinent when accounting for the multiplicity of sources and sets of knowledge drawn from and situated in social and cultural systems. The information sectors incorporated in the construction of health narratives are vital to understanding how narratives are borne of social and cultural context and mediated by internal processes and external factors. With the incorporation of these factors, Kleinman's approach facilitates agency study by providing an entrée into how and why actors make health decisions. Understanding the emic (the patient's perspective) through narratives constructed in part by the patient's descriptions of experience, lay beliefs, and other knowledge is afforded through the approach. In this way, Kleinman's approach allows a systematic analysis of the cultural impact of culture on illness and treatment and, in the case of this study, on breast cancer risk understandings and related agency (Kleinman, 1978, p. 85).

Kleinman's approach is described as both explanatory and ecological (Kleinman, 1978; Kleinman & Seeman, 2000). Explanatory models (EMs) of health "drive behaviour" (Ashton et al., 2003) and inform communication practices of health information in clinical and other settings. EMs are "products of national culture, racial and ethnic culture, gender culture, education and knowledge, social class, religious beliefs, and personality traits" (Ashton, Haidet, Paterniti, Collins, Gordon, O'Malley, Peterson, Sharf, Suarez-Almazor, Wray & Street, 2003, p. 147). As historical and socio-political products, explanatory models "reveal the underlying discrepancies in status and power between the key participants in the health care relationship" (Kleinman, 1978, p. 88). Ecological models are "concerned with the processes and conditions that govern the lifelong course of human development in the actual environments in which human beings live" (Bronfenbrenner, 1994, p. 37). These models seek to account for the dynamic interplay between individual-level factors and social, political and economic factors of the systems in the environment through the life course. Socio-ecological models of health apprehend the complex interrelationships that can affect human and environmental wellness. Kleinman's approach, a model rooted in understanding cultural influences on illness and illness decisions, attempts to capture the multiplicity of the influential factors illustrated in ecological models. Notably, while both explanatory and ecological, Kleinman's approach moves past the individualized, Western, biomedical approach to health and begins to account for socio-cultural influences on health understandings.

# **Contemplating Agency**

In sociological terms, human agency is conceptualized as acting in relation to social structures and often in opposition to those structures. These actions can be individual or collective. In their efforts to conceptualize agency for empirical research, Emirbayer and Mische, in their 1998 paper "What Is Agency," define agency

as a temporally embedded process of social engagement, informed by the past in its iterational or habitual aspects, but also oriented toward the future as a projective capacity to imagine alternative possibilities, and towards the present as a practical-evaluative capacity to contextualize past habits and future projects within the contingencies of the moment" (Emirbayer & Mische, 1998, p. 962).

In this study, agency is spoken of and conceptualized related to breast cancer riskunderstanding and mitigation strategies or actions at multiple ecological system levels. Agency in this frame also includes barriers to enacting agency as perceived and identified by the women in their narratives.

The women's narratives in this study do not necessarily contain the naming of the agency concept. However, agency is illustrated in the meanings the women construct, as well as the actions and strategies they talk about as opportunities for control over breast cancer risks. For the purposes of this research "agency" is understood as the various ways of controlling perceived causal factors or risks for breast cancer the women believe they face in their lives and the context of their work at the Ambassador Bridge. As described in their narratives, breast cancer risk; it is, rather, a problem of context and the lived experiences of the social and cultural systems in which they are situated.

### Points of Interaction in Health Understandings

The points of interaction of the information spheres in Kleinman's approach exemplify the overlap in biomedical and socio-cultural understandings produced by actors in health understandings. The interactions illustrate that the experience of health, disease and risk is expressed through a convergence of knowledge sets through the interplay of internal processes and external factors. External factors include: "social, political, economic, historical, epidemiological and technological factors" (Kleinman, 1978, p. 86), and internal processes include: "psychophysiological, behavioural and communicative process" (Kleinman 1978, p. 86) and a grounding of "beliefs and activities in socio-political structures and in particular local environmental settings" (Kleinman, 1978, p. 86). Internal and external factors influence not only the experience of health but also agency and decision-making. Health narratives can thus be seen as adaptive tasks.

Kleinman suggests a *moral ordering* of information within illness narratives, based on *what matters most* to an individual, group, or society. The moral choices that people make in the face of injustice, suffering and danger are reflections of values, priorities, and local realities. Priorities may include status, jobs, money, family, sexuality, order and control, health, life, religious commitments, political arrangements, "and all sorts of culturally and personally specific agendas" (Kleinman, 2007, p. 6). The concept of 'moral ordering' highlights that decisions are subject to rank, order, and prioritization, the explanations and evidence for these decisions based on what matters most to a social actor.

When incorporated into the narrative analysis, the concept of what really matters is external to Kleinman's approach illustrating three information sectors. However, what really matters may influence how the sectors and the information sourced from them are interpreted, accepted, rejected, or incorporated into health narratives. What really matters is distinctive and "anchored locally, both in a transpersonal and in a subjective sense" (Kleinman, 1997, p. 6). In contrast with nihilist and social science responses that accept the cynical notion that maybe "nothing matters anyway" (Kleinman, 1997, p. 8), Kleinman embraces the opportunity in these iterations of what matters as potentially transformative to the "disordering effects of advanced capitalism which, like some universal solvent, appears to many to dissolve all that matters" (Kleinman, 1997, p. 9). The transformation Kleinman envisions is thus:

By opening up space for critical self-reflection on our world and ourselves, we can prevent ourselves and others from becoming worse people under the pressure of changing conditions. We can protest and resist a dangerous moral ethos in our families, workplaces and communities...we are morally responsible for ensuring that others understand the social injustice our worlds routinely create, including what we have brought about by our own actions. And we are also responsible for doing something about injustice (Kleinman, 2007, p. 24).

Moral ordering, as described here, becomes a call to action, a terrain on which agency is contemplated and prescribed in the process of meaning-making for the subject.

# Moral Ordering of Risk Factors

Using Kleinman's approach, narratives—and the discourses they contain and combine—are understood to be constructed by a process that includes filtering information from various sectors through what matters to a subject. Of fundamental interest is how the diverse risk discourses are woven into narratives by the women, what the narratives reveal about how and why they are woven, how they prioritize certain discourses based on what matters, and how what really matters reflects the embedded and lived context and experience of the subject. The ordering or prioritizing of various breast cancer discourses in the narratives, including the dominant biomedical discourses of genetics, lifestyle factors, and treatments, as well as different discourses about environment and workplace, is instructive in understanding the relative importance or ranking given by women to the variable breast cancer risk discourses. By examining the sources of information used by women to construct narratives, a layering effect—moral ordering based on what matters—is evident. The layers illustrate how and why justifications or rationalizations of specific knowledge sources are constructed, providing insights into why they are interpreted and prioritized in particular ways. These concepts and considerations emerge in narratives as complexities of each story's totality, individual choices, and reflections of the broader systemic and structural influences on life.

The situatedness of narratives for environmental breast cancer risk within their social relationships and institutional (including occupational) settings illustrates the meanings and behavioural norms of those settings and their interactions as constructed through women's understandings. Subject context, including social relationships and institutional settings, are pivotal components of understanding the influences on the construction of socially and culturally based health narratives and the information contained therein. Analysis of relationships and institutional settings, as incorporated in an ecological framework, demonstrates that breast cancer risk experiences are nested set of multi-level and multifactorial relations over the life course. The connections between workplace, community and the individual are "systemic relationships between the components" (Kleinman, 1978, p. 86) that form significant aspects of health narratives. These relationships are constitutive of the ecological framework's mesosystem that sees the individual nested in their relationships and settings, impacted and shaped by them, and negotiates with them.

## Contributions of Kleinman's Approach

The most significant contribution of Kleinman's approach to the study of women's understanding of breast cancer risks, including environmental risks and agency toward control over risks, is its fundamental orientation of the subject in their cultural location. Rooting the subject in their cultural location is a critical component of the analytical framework in grasping women's breast cancer risk understandings. The approach provides for investigating subjective understandings, knowledge-making and meaning-making moving towards improved illness and health responses. These are the pivotal components of the research questions and the findings drawn from the particular group of women interviewed for this study. Kleinman's approach's ecological framework creates a basis to help explain the specificities of women's realities grounded in their contexts. Furthermore, it engenders consideration of the ecology—or the interconnectedness—of the multiplicity of relationships and influences on the subject. Kleinman's approach also allows the incorporation of agency as a way to understand health knowledge, which is of key importance in a study that focuses on the experiences and narratives of women. The production of knowledge by women seen as active subjects in their socio-ecological locations is pivotal to analyzing the narratives they construct in response to the research questions. The approach presents the opening to recognize women as potentially distinct meaning-makers and as active agents nested in their relationships, interactions, information networks and structures.

#### Adapting Kleinman's Approach to Understandings of Risk

Though Kleinman's approach deals with understanding illness and does not talk about the risk of illness, it can be adapted and employed to gain understandings of risk in the realm of environmental health. The approach affords the capacity to: appreciate the placement of the individual in the risk assessment process; view individuals as citizens governed by the system in frameworks that see governance and cultural constructions of power as evident; analyze risk as located within social inequality; seek to understand and reconcile biomedical understandings of risk as they intersect with culture and lay knowledge; and explore agency reflected in narratives of resistance (Porroche-Escudero, 2016), outside the margins of medicine. The capacity to analyze these elements is pertinent when risks originate from an environmental context, affording understandings of how the multiple domains of knowledge and experience intersect with one another in the construction of risk narratives. Aspects of women's narratives that situate the individual within a framework exposing the interplay of structure, governance, agency, and power can have a significant positive impact on health knowledge.

## Limitations of Kleinman's Model

As Kleinman himself acknowledged, the 1978 model has limitations. While Kleinman's model provides the entrée into health understandings from the subject's perspective in their location, the focus is largely on the patient in a clinical setting and does not explicitly situate the subject or their location in a broader social and structural context. Kleinman acknowledged the criticisms that his approach did not have an analysis of power and said he "left a lot out about power, political process, political economy" (Honkasalo & Lindquist, 1997, p. 115). Feminist standpoint theory become a bridge, from Kleinman's approach to patients as clinical subjects, to situate women in a broader context where power and difference also influence agency.

By expanding Kleinman's model approach beyond patients in medical systems to broader social contexts incorporating power and unequal power within relationships and institutions, we can garner an understanding of women's standpoint on illness as captured in narratives. Power conflicts in the health system can be resolved through the adoption of health care strategies that recognize power as constructed within the social context. The "ways that structures of power such as class, age, gender, and disability, intersect and 'conspire' through a web of social beliefs, practices, norms and expectations to shape, and exacerbate, women's experiences of illness" (Porroche-Escudero, 2011, p. 3) as seen from a feminist standpoint adds Kleinman's foundational aspects while incorporating power.

The addition of social determinants of health and social inequality to the theoretical framing adds logical extensions of the analytical framework that place the individual in the risk assessment process and understand agency reflected as resistance narratives (Porroche-Escudero, 2016). The capacity to analyze these elements is particularly relevant when the origin of the risks is environmental or exogenous to the individual and where individual control or choice is limited or difficult.

# **Expanding on Kleinman's Approach**

Kleinman's model exhibits its theoretical underdevelopment in its lack of awareness of conflict and power in the system. As such, it does not enable the fullness of women's perspectives as situated in their socio-cultural contexts. The individual's subjective standpoint and their perspectives of systemic relationships as constructed from their position capture multiple social factors. Enhancing Kleinman's model by incorporating a feminist standpoint facilitates this complexity, providing an entrée into the research questions where women interpret their lives from their subjective standpoint as they pertain to risk.

## Incorporating Feminist Standpoint

Feminist standpoint theory (Harding, 1984, Smith, 1974, 1979, 1997; Collins, 1986, 1990) picks up where Kleinman ends. Feminist standpoint theory and a corresponding feminist perspective provide a bridge between Kleinman's model affording the entrée into systemic and structural theoretical approaches as seen through subjective health and agency understandings. This includes the social determinants of health and the role of power, importantly inclusive of gender.

Social theorist Karl Marx, who started with the worker's standpoint for his social analysis, which was in and of itself a break in convention, influenced Dorothy Smith, who similarly begins with women's standpoint, which puts into effect a deconstructive science. These starting premises direct the interrogation with in-depth analysis while dispensing with assumptions that may pervade dominant perspectives (Wacquant, 2002). Feminist standpoint theory sees knowledge as socially situated and is particularly attuned to giving voice to marginalized populations, thus focusing on where and how inequities in power relations are experienced by marginalized groups (Smith 1974, 1987; Collins, 1986, 1990). A critique of the material relations of women and power emerges through their knowledge production. Just as Smith challenged sociology, Harding challenged science, and Collins challenged institutional and white knowledge, the women in the study may challenge hegemonic knowledge and open space for locating their lived experience and the knowledge as told in their narratives.

The nature of the study questions, coupled with the macro/structural aspects of the issue of environmental risks for breast cancer, lend themselves to the incorporation of feminist standpoint theory. The theory fosters investigation of the ruling relations of a particular context through the discovery of the thoughts people have and how those thoughts structure the world they live in (Smith, 2005). Environmental breast cancer risks remain an area of contested science (Carroll, 2004), rooted in contemporary ruling relations (Smith, 2005). Through standpoint theory, investigating ruling relations through narratives is a way to discover the structures of women's lived experience and knowledge. The standpoint premise firmly establishes the subject as the knower and creator of such socially specific knowledge (Smith, 2005) and offers a way into understanding contextually specific settings, practices, and relations that produce, coordinate, and construct risk perceptions.

"Talk and text" as the coordinator of women's consciousness in their subject location is the ground on which the social problem of breast cancer risks can be analyzed using narrative and discourse analysis (Smith, 2005, p.76). Narratives that challenge hegemonic ways that meaning-making for breast cancer occurs, including the responsibilization of the individual woman, cast women as "agents of meaningmaking in the context of unequal power relationships between the person and the world surrounding that person" (Porroche-Escudero, 2011, p. 19). Narratives can be explored for "the impact of underlying power dynamics and normative gender constructions on women in relation to illness and narrative" (Nielsen, 2019, p. 44).

While standpoint theory centres women's knowledge production, what is already known of breast cancer from women's standpoint is vital to applying this theoretical lens. Research brings out that "culture has influenced what we know and do not know about breast cancer" (Ferguson & Kasper, 2002, p. 2), and society and social institutions have shaped the experiences of the disease. Gender is a key aspect of breast cancer's subjective experience, and standpoint theory facilitates capturing that specificity. Women's breast cancer experiences are "inextricably woven with their social worlds" (Rosenbaum & Roos, 2002, p. 153) and the pervasive cultural meanings that surround the disease. Discourses of breast cancer that tend to focus on individual women remove them "from the communities, institutions and societies in which their experiences are taking place... and therefore, the issue of breast cancer is depoliticized and decontextualized" (Fosket, Karran & LaFIa, 2002, p. 320). Standpoint theory is positioned to understand the marginalization resulting from breast cancer's dominant discourses as separated from the subject location and which can be intensely political.

A perspective that recognizes women's experience as political is critical given that breast cancer is not just a personal problem but is an experience constructed through social context. While the pervasive discourses tend to limit the breast cancer experience to a specific set of meanings, "for others, rejection of these meanings provides the basis for defining women-centred and less-oppressive ways of relating to the breast cancer crisis" (Rosenbaum & Roos, 2002, p. 177). From a women's standpoint, agency can be uncovered and analyzed to understand women's knowledge of environmental breast cancer risks and mitigation strategies. Barbara Brenner's (2002) study of the roots of activism in the breast cancer movement wrote that women recognized that prevention would come through action and demands that breast cancer problems be addressed. The exercise of agency by these women came from their "personal experiences of the illness and in their willingness to use their strength" (Brenner, 2002, p. 326) through political action.

Women's vast knowledge and interpretations of the locally produced understanding sheds light on the ways breast cancer risks are manufactured by society, with risks always interpreted and constructed within narrative frameworks. This study seeks women's knowledge as additions and potential challenges to what is already known and constructed about risks. In many ways, women have to ignore their principal narratives to grapple with and deal with their own understandings. This includes appreciating how their understandings have been suppressed both locally and

39

beyond with the relations of ruling. Including women's interpretations as part of that situatedness and context can counter the neoliberal individualization of risk.

Women's standpoint, which allows for the examining of uncertainties, situations and external factors, including the marginalization of their experiences through ideological understandings that centre male experiences, is in line with Kleinman's concept of prioritizing and ranking through moral ordering. Women can narrate what matters to them, interpret their lives from their perspectives, and accept or challenge them. The contexts and conditions of women's lived experience allow them to deal with risk in specific ways. Without an understanding of their perspectives, the pervasiveness of the contexts that produce breast cancer risks cannot be challenged by relevant risk mitigation strategies.

Beginning with women's subject location logically moves the theoretical orientation to standpoint theory and recognizes women's bifurcated knowledge (Smith, 2005, p.11) that includes dominant knowledge systems that claim to portray women's experience overwhelm it through male-oriented language and understandings. This is key to situating women's understandings, including through their own knowledge and perspectives on ruling relations, power, conflict, and everyday practices as problematic. The feminist standpoint adds to and enhances Kleinman's approach of locating the subject within cultural systems while further grounding it as an ecological approach, capturing the nested set of relationships from the micro to the macro, and incorporating institutional, legislative, regulatory, political, economic and social implications. Approaching the study from the perspective of women frames the research around the question of what is known from women's knowledge and understandings, with context recognized as influencing interpretations. The subject location from which the research begins opens the door for the consideration of different knowledge systems in narrative construction, thus creating the possibility for feminist knowledge production.

# Incorporating Structure Through the Lens of Agency

Given this study's line of inquiry on agency, a socio-ecological theoretical framework—which recognizes the nested and complex set of relationships of the individual in multiple levels of the systems of structures (Bronfenbrenner, 1977; Schettler, 2015; CHE, 2020)—provides a basis to analyze components of the concept of agency including power, conflict and tensions in the narratives. While Kleinman's approach is described as ecological, his model does not fully capture the multiplicity and complexity of the ecological levels, interrelationships of socio-cultural contexts. For the most part, Kleinman's approach situates the individual as a patient in a medical context influenced by culture but stops short of proving a depth of engagement with overarching systems or structures. The inclusion of systemic relationships including multiple intuitional influences on medical problems, enhances Kleinman's approach.

Placing breast cancer risks in their social environment recognizes the connection between health and social determinants of health as encompassed in the socio-ecological framework. Determinants such as income, support networks, education, employment, social environments, physical environments, coping skills, resilience biology, services, gender racialization, culture, history and more (Marmot & Wilkinson, 2005). In recognition of this—and keeping with the ecological framework

which accounts for power in relationships and institutions—the ways in which individuals view their interactions with these social determinants of health and social inequality as seen from women's standpoint are incorporated into the analysis. Thus, the theoretical trajectory moves from Kleinman's model locating the subject, bridged by standpoint theory, to the role of agency as influenced by relationships of power.

Addressing agency, starting from Kleinman's theoretical perspective, stems from what he describes as core adaptive tasks performed by the health care system (Kleinman, 1978, p. 87). Kleinman's core adaptive tasks include the construction of strategies and evaluation to guide [health] choices, deliberate and non-deliberate health-enhancing (primarily preventive) and health lowering (sickness producing) behaviours as well as the management of a range of outcomes (Kleinman, 1978, p. 87). These are cultural and psychosocial functions in the face of sickness and healing and can be illustrative of social actors' moral ordering. Adaptive tasks are also applicable to health risks as taken up by social actors. Therefore, they are instructive in analyzing agency within narratives about risk, particularly in recognizing what Kleinman points out as institutionalized conflicts built into health care systems. In Kleinman's approach, adaptive tasks are uncontested and presented as a natural or logical movement towards improvement free from conflict. This conception is problematic in that it fails to recognize the material and experienced realities of health adaptations. While useful as a starting point, the concept of adaptive tasks needs further development by recognizing that as a society changes, the people in it are likewise changed, and play a crucial role in these changes. Societal adaptations around health and healing questions are better understood within the context of the ideology

operating, in this case, neoliberal capitalism, a defining feature of present history. Agency must be understood as part of a process of adaptation and change.

Improvements and adaptations occur in different sectors—or through the various ecological model levels—by actors who contribute their perspectives to change directions. As Kleinman's approach fundamentally is, functionalist theories are problematic in that evolution through change is organic. Functionalism fails to recognize the many influences of the changes in directions. Kleinman's contribution to adaptive tasks is important, but his model's basic underlying assumptions miss the issue of conflict. Still, through greater openness towards and receptiveness and understanding of what matters to women, it becomes possible from women's standpoint to capture the conflict that Kleinman's model misses while also recognizing adaptive tasks as agency sites for social change.

By extending the core adaptive tasks' ideas and refining the concept of what matters to women, women's subjectivity and agency can be incorporated into capturing breast cancer risk responses. Moreover, applying the core adaptive tasks with these enhancements incorporates the critical concepts of power and conflict. Rooted in the subjective location, bridged by feminist standpoint, investigating women's agency around breast cancer risk can capture inequalities that pervasive narratives of risk fail to, from the individual or local level to larger social narratives of breast cancer risk.

## Narrative Analysis Through the Theoretical Lens

Narratives illustrate how women work to convert the complexity of health understandings and uncertainty about breast cancer risk into understandable, manageable, subjective understandings. Though women incorporate objective realities into narratives (such as knowledge of genetics, lifestyle, and environmental risks), seeing the narratives through a socio-ecological lens explains how knowledge systems are utilized, how certain domains are privileged over others, and how women make sense of breast cancer risks within their contextual specificities. The fundamental approach to narrative analysis through theory is that the experience of breast cancer risk is a complex relationship between the individual and the broader social, political, and discursive contexts in which the risks are lived. Understandings of illness are both cultural and social; they are "not simply systems of meaning and behavioural norms, but those meanings and norms are attached to particular social relationships and institutional settings" (Kleinman, 1978, p. 85).

Narratives are emblematic of the complexities of the social world in which they are rooted and can serve the function of "providing personally and socially meaningful explanations" in the management of health (Kleinman, 1978, p. 87). Narratives of risk can contribute knowledge to understanding along the health system continuum, from prevention to risk, illness, diagnosis, and treatment. Narratives acknowledging structural relationships and institutional factors focus on the full experience of health while including enacting or strategizing agency opportunities within a socio-ecological framework. In many ways, women disregard the primary dominant cultural narratives in order to contend with their own understandings, including how their understandings have been suppressed both locally and beyond with ruling relations. Culture, medicine, and structure have a major influence on the experience of risk and the narratives that describe those experiences. Therefore, "thinking about this [breast cancer] as an ecological challenge helps us identify multilevel interventions that will reduce breast cancer risk and improve outcomes" (Schettler, 2014, p. 16). As a result, an analysis of how women understand and integrate environmental knowledge within their narratives, as seen through those same settings, facilitates new and better approaches to strategies for knowledge translation, knowledge mobilization, regulatory and policy modification and creation, risk mitigation at the individual and collective level, and in setting priorities for future research investment.

## **Theoretical and Analytical Approach Summarized**

This dissertation examines how women who work in an environment with an identified risk of breast cancer construct understandings and narratives of their risks and how women perceive and exercise agency in the acceptance, avoidance or negotiation of those risks. Building on what is known from prior studies, this disseration examines illness narratives, perceptions of risks, the discourses operating around breast cancer risk, the ambiguities of environmental exposures and associated risk, and what information may prompt behaviour or other socio-cultural environmental changes. Gaps in the literature regarding women's agency around breast cancer risks are addressed, while taking structure and power into account. This dissertation also contributes to knowledge translation of risks for environmentallyrelated breast cancer and understanding how women weigh risks in their decisions about how, or whether, they can act on knowledge of risks at the personal and/or collective level. As the relevant literature reviewed in the forthcoming chapter illustrates, health narratives incorporate biomedical understandings and socioculturally grounded understandings.

This study's narratives are produced by women from a specific work environment with its localized conditions and intrinsic workplace culture. Due to the breast cancer risks present in their workplace, their subjectively located breast cancer risk narratives challenge the hegemonic knowledge produced by biomedical, corporate and media systems that tend to omit occupational and environmental risk factors for breast cancer.

Analyzing breast cancer risk narratives should be attuned to the social and cultural shaping that influences women's experiences and understandings as incorporated into their descriptions. These aspects are evidenced when women speak of beliefs, expectations, roles, relationships, experiences and values. Analysis of the women's understandings as seen through their narratives reveals the construction of risks for breast cancer as both reflective of, and expressions of, experiences of risk as part of a more extensive cultural system that brings together knowledge from the professional, folk, and popular sectors, as value-based or moral decisions.

The theoretical concepts as outlined above are incorporated in the study design to understand and reconcile biomedical understandings of risk as they intersect with culture and lay knowledge. The concepts also towards understanding agency reflected as narratives of resistance, to analyze risk as located within social inequality, and to recognize and analyze the placement of the individual in the risk assessment process and as a citizen governed by a system where cultural constructions of power are evident. Analysis of these elements is particularly critical where the origins of risks are environmental or exogenous to the individual, and significantly, where individual control or choice is difficult or impossible. The research will extend Kleinman's approach to understanding the dichotomies inherent in concepts of agency and power, seeing them as both limiting and enabling. Complementary theoretical concepts help draw out the ecological relationships and institutional arrangements, including how health is organized as distinct and separate from occupation, thereby privileging certain narratives. The institutional conflicts that arise in health and risk relationships and the corresponding narratives illustrate complications in societal and culturally-based healthcare approaches.

As they emanate from their subject location, the women's narratives add to health knowledge with their perspectives providing nuanced explanations of environmental risk factors and power inequalities. In this way, the narratives provide a method of theorizing power inequalities in health through lay knowledge (Popay et al., 1998). The collection of narratives captured through the interview process demonstrate how power manifests through agency investigation, which produces this inherent dichotomy of agency and power. As seen through women's knowledge and understanding of agency, the value in identifying and analyzing the power dynamics creates a broadened conception of adaptive tasks exercised in health. Identifying power—and inequalities within power relationships and dynamics—facilitates resolving conflicts in the system towards adopting more effective health strategies. The added dimension of situating power, and differences in power, as constructed within the social context, and looking at the "ways that structures of power such as class, age, gender, and disability, intersect and 'conspire' through a web of social beliefs, practices, norms and expectations to shape, and exacerbate, women's experiences of illness" (Porroche-Escudero, 2011, p. 3) are essential to this process.

While this research centres on gender as a power relations site, this model is also apt for other explorations of difference and power using an intersectional lens. The narratives collected from the women at the Ambassador Bridge, analyzed through the theoretical framework of women's subject location and how their standpoint highlights the impact of structure on agency, allows for the exploration of both the understandings of environmentally related breast cancer risks, and risk mitigation strategies.

# **CHAPTER THREE**

# Analytical Framework for the Study of Breast Cancer Risk Narratives Dominant Discourses and Representations of Breast Cancer: A Review of Literature

The dissertation's overarching objective is to explore women's understanding of environmentally related breast cancer risks and risk mitigation strategies and how they guide their responses. Notably, the study aims to understand women's knowledge and experience of breast cancer risks and whether or how biomedical and corporate discourses have shaped understandings. The critical insight offered through this approach explores how risk information, discourses, representations, and experience influence the regulation of women's lives and knowledge about their realities. It is also crucial to investigate whether they accept and adopt the dominant biomedical and neoliberal discourses or construct alternative explanations or discourses of resistance that emerge from their subjective knowledge. Exploring the role of social factors and how they underscore women's agency around breast cancer risk mitigation strategies is also fundamental to the research. The dissertation is guided by the research questions and literature that contribute theoretically and methodologically and by the analytical and interpretive frameworks utilized in the study. A review of the relevant literature follows.

There is a growing literature on the science of environmental links to breast cancer. What is less known, and where there is a paucity of literature, is the social science understandings of environmentally and occupationally related breast cancer. In particular, there is a gap in the literature in the frame of how women in an occupational environment with known breast carcinogens construct understandings of environmental breast cancer risks and, relatedly, how they form action strategies for environmental breast cancer risk mitigation.

As outlined in the previous chapter on the theoretical approaches grounding the study, a socio-ecological approach influences the dissertation's conceptual framework. This framework also informs the organization of this chapter. More specifically, the sub-sections of the literature reviewed relate to the various levels of the socio-ecological framework (see Figure 2), starting with the individual through the system (Bronfenbrenner, 1994). The model's individual level relates to the literature on behaviour change and continues through multiple and nested relationships and ecological framework interactions.

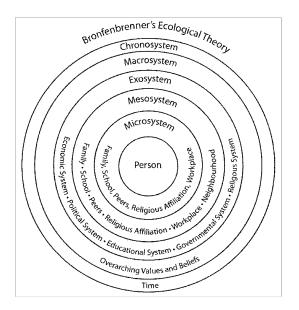


Figure 2: An Adapted Illustration of Bronfenbrenner's Ecological Theory

The illustration, an adaptation of Bronfenbrenner's Ecological Theory, first developed in the 1970s and modified over time, shows the nested set of structures (or relationships) in the ecological environment, moving from the innermost level, the person, to the outermost, the chronosystem, representing the passage of time. Each level has distinctive features (Bronfenbrenner, 1994, p. 39; Stanger, 2011).

As applied in this study, a brief exploration of the concept of risk precedes the review of the relevant literature. The literature is organized into the following chapter subsections: behaviour change; discourses as components of narratives; illness narratives and breast cancer (counter) narratives; feminist perspectives; and locating the environment in breast cancer risk perception. There is some unavoidable overlap as these sub-sections share deep connections. The chapter concludes with a description of the integration of study objectives with crucial aspects of the literature.

# The Concept of Risk

By definition, risk is about exposure to danger (oed.com, 2019). It is also about the possibility, probability, or expectation of exposure. Hence, risk encompasses a level of uncertainty by its very nature, making risk understandings and mitigation strategies complex and multifaceted. Risk theories gained prominence in the 1960s, and later, sociological understandings of risk replaced narrow discourses about acceptable levels of safety with a broader debate about the sociopolitical conditions of risk (Beck, 1986; Giddens & Beck, 1992). Risks produced by industrial societies are 'manufactured uncertainties' borne of their social, political, cultural, and economic contexts (Beck, 1996). Notions of risk are inextricably bound up in political frameworks as "an extension of existing macro-sociological frameworks," and shed light on institutional and organizational governance (Beck & Kewell, 2014, p. 293).

The term risk is often a signifier for uncertainties concerning health, where health risks are less a set of objective scientific facts and more so relational, socially constructed assessments. Popular discourses of risk tend to simplify understanding and management of risks for many aspects of contemporary living (e.g., the risk of failure, a traffic or air accident, being a victim of violence, sexual assault, and health risks). What is known as risk and why a condition is deemed risky is a modern particularity where individuals are expected to learn to manage their health risks (Castell, 1991). Western ideas about health, including disease risks, causes, diagnoses, and treatment, are mainly in keeping with a Weberian idea of rationality (Mueller, 1979), where modernity and neo-liberal capitalism fundamentally define the ideas and shape the values that inform the expectations of actors' responses to social and health risks (Gordon, 1991; Petersen, 1996; Burgum, Raza & Vasquez, 2017). Health risk discourses frame and influence subjects to see risks in particular ways. Risk management messages place responsibility with the individual, reducing risk and make corresponding personal decisions or individual behaviour modifications.

Under neoliberalism, wherein individual subjects are held responsible for governing social risks and life in society, regulation of problems is transposed to "care for the self" (Petersen, 1996). Likewise, for breast cancer risk, "the individualization of health and illness has resulted in a 'responsibilization paradigm'" (Sweeney, 2014, p. 950). The focus of risk management for health generally and breast cancer, more specifically, has primarily been lifestyle and personal behaviours. The master narrative of individual responsibility surrounding breast cancer risk decontextualizes health-risk knowledge and decisions about risk mitigation. The individual's construction as the locus of action obscures the social context in which the person and breast cancer risks exist. This individualization coincides with the dominant epidemiological paradigm of disease and illness, where anatomy and physiology are central. The hegemonic outlook on disease emphasizes "individual behavioural factors rather than environmental and social factors as keys to disease prevention" (Brown, 2006, p. 21). The framing of the individual as responsible for and in control of health risk conceals the reality that many environmental and social factors influencing health are involuntary or beyond individual control.

Despite evidence of environmental factors causing breast cancer, it is still, for the most part, viewed in the predominant discourses as a disease of genetics, lifestyle choices or bad luck, with causes and risks limited to the body and individual-level explanations (cancer.ca). An alternative conceptualization of risk sees women's overall health experience, not just at the individual level, but as holistically, wellness-focused and situated in a socio-ecological framework where systems interact with and upon the individual (Bronfenbrenner, 1994; Schettler, 2015). The multi-level complexity of individual interactions within families, communities, ecologies and global environmental relationships dynamically influence the health of all parts of the system. Resources, meanings and priorities of health are shaped by context and "context matters at a structural and political level" (Armstrong & Pederson, 2015, p. 358). This orientation leads to seeing wellness (including questions of risk) from a collective, rather than an individual perspective, and situates wellness in its systemic context (Kleinman, 1978; Falquist, 2009; Sweeney, 2014). Agency enacted for health and wellness is also necessarily rooted in a social context instead of exclusively individual actions.

Risk and risk management are more significant than the narrow conception of the individual and their bodies' mitigation of risks. Individuals are either subjected to or shielded from risks in their social environments. Health and health risks in social environments connect strongly to income, support networks, education, employment, social environments, physical environments, coping skills, resilience biology, services, gender racialization, culture, history and more. These factors can be broadly categorized as environmental, though in the social sciences, are more typically understood as and referred to as "social determinants of health" (Marmot & Wilkinson, 2005).

The study of individual responsibility for environmental health risks as a social issue emerged in the 1990s (Hallman & Wandersman, 1992). Environmental health issues tended to be regarded as objective problems of science, rather than matters where subjectivities, socially constructed ideas, norms and values are interpellated to individual subjects (Keune & Kopnina, 2010). Social scientists note the absence of a critique of the focus on the individual concerning environmental harms (Falquist, 2009). The tendency to responsibilize the individual creates an unspoken acceptance of a functionalist approach in contrast with a systemic or ecological approach (Bowden, 2010). Challenging the widely accepted assumptions of individual responsibility for breast cancer risks, especially those stemming from environments by recognizing the interplay of personal and structural risk factors related to breast cancer is a pivotal aspect of this study's frame of analysis.

## **Behaviour** Change

There is a broad literature on health behaviour, consistent with dominant ideas that health outcomes are tied to personal behaviours. Findings reported in the literature on behaviour change related to health are variable. Changing behaviours is challenging and complex (Marteau & Lerman, 2001; Green, Hamen, Cooley, 2015). Adopting health-promoting behavioural changes is influenced by patient values and goals and other social, emotional and health goals (Henry et al, 2019). Recognizing patient experience, attitude, and everyday life experiences in communication transactions between clinician and patient are essential to the understandings within health communications, including the need to "address social functioning and family roles," as biomedical education alone may not be sufficient (Fancher, Ton, Le Mayer, Ho & Paterniti, 2010, p. 265). Individuals and their behaviours are better understood as nested in socio-cultural relationships that influence personal decisions and health outcomes.

The findings on behaviour change related to cancer risks are conflicting. Cancer agencies and public health communications suggest that communication and interventions affect precipitating changes in behaviour to reduce risk, including improving diet, increasing exercise, and smoking cessation (cancer.ca). Some studies show reductions in lung cancer associated with tobacco education programs (Barnoya & Glantz, 2004). However, it has been shown that education must be accompanied by clinical support for exposure to tobacco and smoking cessation programs to be effective (Warren & Commings, 2020). Other research, including a 2016 metaanalysis of communicating genetic cancer risks, found little to no effect in precipitating behavioural changes by individuals (Hollands et al., 2016). A multiplicity of studies examining personalized health communications, as reviewed in a 2017 meta-analysis, reveals no substantial effect on behavioural changes (French et al., 2017). The ongoing focus of communications regarding behavioural changes as a breast cancer risk mitigation strategy is called into question with these findings. Further adding to the ineffectiveness of the focus on individual behaviours to

precipitate change and reduce risk is the complexity of controlling exposures originating in environments.

A holistic understanding of health's nestedness within an ecological framework, paired with the scientific understanding of specific biological mechanisms, reveals multiple agency areas beyond the effect of individual behaviours. Current data on breast cancer incidence, including increases in some demographic and geographic populations (younger women, women in high exposure pathways, women exposed to endocrine-disrupting chemicals) (Grey et al., 2013), suggest a need for structural understandings. The key to these understandings recognizes the nestedness of environmental risks from micro to macro levels, thus the interconnectedness of the relationships in socially based risk factors for breast cancer (Schettler, 2015). Breast cancer risks through the micro, meso, exo, macro, and chrono levels comprise exposures such as genetic variations that may occur in utero due to chemical exposures, air pollution during identified biological windows of vulnerability for girls and women including at menarche, before first birth and menopause. As well, the mixtures of exposures from consumer products including those used for self-care and which contains endocrine-disrupting chemicals in small doses (Rodgers, Udesky, Rudel, & Brody, 2018). Involuntary exposures to breast carcinogens at critical windows of vulnerability along with combinations of exposures at critical periods over the life course (e.g., in utero and pre menarche exposures to endocrine-disrupting chemicals) highlight that control over some risks is not tenable through individual behaviour strategies (Gray, Rasanayagam, Engel & Rizzo, 2017).

56

Women's environmental health researcher and policy analyst Ellen Sweeney detects that master narratives of the individualization of risks obscure the complexity and social contexts of breast cancer risk experiences (Sweeney, 2014). The omission of environmental risk factors in master narratives contributes to a gap in risk mitigation strategies to address those same factors. Sweeney observed the failure of the regulatory regime to enact a primary prevention approach for women's health and argues the "emphasis on behaviour at the level of the individual does not encourage political and collective action that may be targeted at long-term and more broadly focused solutions, including regulatory reforms" (Sweeney, 2014, p. 953). Structural supports, including regulatory, policy, economic, and cultural reforms that involve multiple levels and actors to enact controls in addition to personal behaviour level risk mitigation are necessary for effective breast cancer risk mitigation for environmental exposures (Brody, Moysich, Humblet, Attfield, Beehler, Rudel, 2007; Ackerman, Attfield, & Brody 2014; Dodson, Nishioka, Standley, Perovich, Brody & Rudel, 2012).

Given that the literature reports limited effectiveness on behaviour change related to cancer prevention, coupled with the understanding that many exposures to carcinogens are involuntary in external environments, the targeting of individual behaviour changes for cancer prevention is too narrow. Strategies aimed at breast cancer prevention should be conceptualized and understood in broader contexts that include socio-cultural influences and structural factors, and importantly, values. Cultural ideas and embedded values operate at the individual level and through systemic relationships, including ideology. Recognizing that breast cancer is not only abnormal cells in an individual body but, rather, a disease produced in socio-cultural contexts is key to understanding and addressing the effectiveness of risk mitigation strategies (Schettler, 2015). Like the individuals they related to, behavioural changes are nested in a socio-ecological structure, and therefore risk mitigation strategies focused solely on individuals' actions are missing critical aspects to target agency for breast cancer risk management effectively.

## Discourses as Components of Narratives

Breast cancer discourses as reflections of social knowledge, practices and governance are vital to investigating women's understandings of breast cancer risks, and the social factors that contribute to and shape breast cancer discourses are numerous. As components of narratives, discourses facilitate identifying and analyzing external social forces that contribute to women's construction of narratives. The frameworks within which women experience and understand risks contribute to how they perceive decisions about risk management.

When applied in a sociological context, discourse diverges from its origins as merely a linguistic category and is treated as a "distinctive category of thought" and an intertextual reality within a particular socio-historical context (Chalaby, 1996). Discourse becomes an object in and of itself, created and applied by social actors within socio-historical dimensions, text, and a class of texts (Chalaby, 1996). Analyzing discourse provides an entrée into how social phenomena are understood and constructed, including where power relations are embedded in discourses (Gutting 1989; Gutting, 1998; Jessop, 2007; Lemke, 2002).

Social forces can be hegemonic, reinforce power from above, and contribute to the (re)production of discourses, including women's everyday experiences at home and work. Information sources that contain the discourses that contribute to the production of breast cancer risk narratives include various sources from socio-cultural contexts, including the medical system and personal experience. There are inherent disparities in power between discourse producers and women as subjects in biomedical, state, corporate public relations, pharmaceutical companies, nonprofit organizations, and other discourses (Ferguson & Kasper, 2002). Some of the sources women incorporate into risk narratives are reflections of power through discourses from above. Discourses from below, contested discourses and subjugated discourses that challenge or shift the dominant discourses also emerge in women's risk narratives. Discourse analysis as a component of investigating narratives exposes how women and other marginalized groups produce disruptive or resistant narratives that shift knowledge, ideas and subjectivities and counter or challenge hegemonic discourses. Discourses, made visible through analysis of women's agency narratives, are useful for understanding power, illustrating both acquiescence and resistance (Jones & Porter, 1994).

Breast cancer discourses that foreground genetics and lifestyle risks are more prevalent than environmental and occupational risks despite mounting scientific evidence of occupational and environmental contributions to breast cancer. Exploring breast cancer discourses as components of knowledge and governance is essential in conceptualizing how the lifestyle argument persists in institutional and cultural practices. Whether and how women adopt dominant discourses in enacting their agency on breast cancer knowledge and whether and how women incorporate occupational and environmental discourses are vital narrative analysis pieces (Foucault 1963; Gutting, 1989; Lemke 2002; Lemke 2003; Prodinger 2015).

The news media are significant among discourse producers and social influences. While providing health information, the media produce and present cultural ideologies through discourses made up of images, concepts and premises that comprise the frameworks for representation, interpretation, understanding and sense-making of social phenomenon (Hall, 1993; Fosket, Karran & LaFIa, 2002). Cultural accounts of cancer expressed through discourses are not merely representations of facts or information. Instead, they "transmit larger metaphorical and ideological ideas about illnesses" and the experiences of cancer by those who live with it (Fosket, Karran & LaFIa, 2002, p. 303). The literature on discourses of breast cancer in the media identifies patterns, consistent themes in discursive strategies and variations across communications mediums, including news reports, documentaries, advertising, and fundraising campaigns. Analyses of breast cancer discourses reveal that media reflect and contain particular social discourses operating, including those from biomedical and corporate sources.

Numerous studies of breast cancer media discourses identify the prevalent themes of awareness-raising and pink ribbon fundraising, biomedicine, survivorship, consumerism, individual responsibility, genetic causation, treatments, and detection (Brown et al., 2001; Atkin, Smith, McFeters & Ferguson, 2008; Atkin & Smith, 2010; Nelson & Salawu, 2016; McGannon, Berry, Rodgers & Spence, 2016; Champion, Berry, Kingsley & Spence, 2016). Other studies on breast cancer discourse bring out the tendency to infantilize and reinforce patriarchal attitudes and practices in the media, medicine, and science. The discourses render women to a state of passive, cheerful little girls, adorned in pink (Ehrenreich, 2001). Also of importance: studies find little to no discursive content on primary prevention or environmental risk factors (Brown et al., 2001; Atkin, Smith, McFeters & Ferguson, 2008; Atkin & Smith, 2010; Nelson & Salawu, 2016; McGannon, Berry, Rodgers & Spence, 2016; Champion, Berry, Kingsley & Spence, 2016).

In their study of the representation of breast cancer in popular women's magazines in the United States from 1913 to 1998, Fosket, Karran and LaFla (2002) reported that magazine discourses communicated that breast cancer is caused by either lifestyle behaviours or women's bodies. The paper observes that those dominant ideologies of femininity, individuality, and personal responsibility for breast cancer emerge out of and are reinforced by media discourses (Fosket, Karran & LaFla, 2002, p. 305). This focus on the individual and responsibility has the effect of shifting the focus "away from larger social, environmental, political and economic issues" while placing the blame on women (Fosket, Karran & LaFla, 2002, p. 304).

In the Canadian context, two studies find key trends and dominant discourses evident in a Canadian daily newspaper from the period 2002-2016. The first study finds that discourses are comprised of: lifestyle and genetics; cheerful warriors; normalizing; pink products and fundraising; early detection and treatment; and the general omission of environmental and occupational risk factors for breast cancer (McArthur & Winter, 2014). Building on the 2014 study, a follow-up finds that the lifestyle and genetics discourses in the articles studied drop throughout the years, while the portrayal of women as cheerful warriors and survivors becomes the most prevalent discourse (McArthur, 2017). Occupational and environmental discourses are the least frequently occurring discursive themes in the articles analyzed, and by the end of the study period, are omitted entirely (McArthur, 2017).

Silent Spring Institute's dedicated research focus on breast cancer and environmental exposures report fewer than half of breast cancer organizations include information on environmental chemicals on their websites (Silent Spring, 2019). Over 80% focus on risk factors such as exercise, diet, family history, or genetics (Silent Spring, 2019). This disparity in information contributes to uncertainty about environmental risks for breast cancer. The study's authors underscore the need for environmental breast cancer experts and cancer organizations to increase research translation activities to communicate science on environmental factors in their work.

Rosemarie Tong researched the negotiation of personal and political responses related to breast cancer. She observed that the biomedical view of the heroically passive breast cancer patient dominated discourses (Tong, 2006). The portrayal is not surprising given the frequent depictions of women as warriors and survivors celebrated for their compliance with the medical regimes. Dominant ideologies are entrenched in illness discourses and shape "what are often mistaken to be neutral narratives" (Fosket, Karran & LaFIa, 2002, p. 303). Compliance and disempowerment reflect the expansion of medical power beyond clinical settings into women's experiences of illness via media (Pitts, 2004) and may contribute to a lack of political responses to the breast cancer epidemic in women's lives.

The recurrent inclusion of women's biomedical perspectives in constructing their cancer narratives does not necessarily mean that medical facts prevail. Women's biomedical perceptions of risk often contain inaccuracies (Woloshin, Schwartz, Black & Welch, 1999; Hopwood, 2000; Aduayi, Onayade, Aduayi & Odu, 2015). While biomedical perspectives are incorporated, perceptions of risks are often derived from acquaintances (Henriksen, Guassora & Brodersen, 2015). Suspicion and distrust of medical knowledge result in acquaintances' voices having more authority in some working-class communities (Belsham, 1991; Dunk, 2003). Decision-making occurs through the formulation of perceptions and heuristics (Katapodi, Facione, Humphreys & Dodd, 2005). Links made by people between their risk perceptions and the resulting health-protective actions they adopt needs further development and research (Rimal & Juon, 2010; Palasaolo-Harris & Skirton, 2016).

The literature on cancer risk communications reinforces that risk understandings develop in part from the discourses embedded in various information sources, including biomedical knowledge and cultural and social influences. The findings suggest it is vital to analyze how the multiplicity of discourses operating through the socio-ecological system levels come together and contribute to the construction of health understandings, including environmental risks for breast cancer. Identifying the multiple influences from women's social and cultural relationships and contexts incorporated into risk narratives illustrates that subject agency is part of the formulation of risk understandings. Women weigh discourses and dominant meanings with personal and social experiences of breast cancer, but the pervasiveness and nature of prevailing social models can silence women's experiences and responses to breast cancer (Rosenbaum & Roos, 2002, p. 178). Narratives and the discourses within them contain unique aspects of women's perspectives and common structural influences,

illuminating how women are situated contributes to shaping their understandings. The roles of the variable discourses in women's breast cancer risk narratives present underdeveloped elements of how risk mitigation strategies can constructed to greater effect.

Considering the study question of how women understand and act on knowledge of breast cancer risks, the content and origins of discourses circulating are essential aspects to address. Elements of scientific uncertainty around environmental risks for breast cancer remain. Communicating the nature of the uncertainty is imperative because "not communicating uncertainty blurs the contrast between evidence based-recommendations and those without evidence" (Tarn, Paterniti & Wenger, 2016, p. 909). The absence of evidence is essential to note when considering the effectiveness of recommended actions, but distinctions must be made between the absence of evidence and other forms of uncertainty. Uncertainty due to the omission of information (including in media and other discourses as discussed above), or the manufacturing of uncertainty in environmental risks for breast cancer, reflects structural power disparities and ideological interests.

The manufacturing of uncertainty about environmental and occupational links to cancer by corporate and industry interests who benefit from fewer regulations is a particularly detrimental classification of uncertainty (Michaels & Monforton, 2005). The inherent uncertainty of the scientific and epidemiological methods utilized in determining links between exposures and cancer development is exploited as a strategy to justify corporate and government inaction (Michaels, 2006; McGarity & Wagner, 2008; Walker, 2017). The absence of proof serves to undermine protective measures for risk mitigation where exposures to risk for breast cancer are beyond individual control, such as in the general environment, in work environments, or in products for consumption that are assumed to be safe (Trasande, 2019; Silent Spring Institute, 2020). Implementing safeguards to consumer, worker, or community health, whether through engineering changes, protective equipment, substitutions, or other measures, can be costly. Manufactured uncertainty is leveraged against policy, legislative and regulatory processes to avoid additional costs (Andsager et al., 1999; King, 2008; Michaels, 2006).

Further complicating matters, definitive proof of a particular cause of cancer in an individual case, is difficult, if not impossible, to ascertain. The body of evidence of associations for causal factors for cancer stems from large volumes of population data. The absence of "proof" becomes equated with uncertainty, invoked as a rationale for lack of action. The weight of evidence of associations should be sufficient for action and implementation of the precautionary principle, which states that "When an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause-and-effect relationships are not fully established scientifically" (Kriebel et al. 2001).

The phenomenon of manufacturing uncertainty, paired with the individual responsibilization of risk, subordinates the risk's structural conditions in dominant breast cancer risk discourses. The subjective experience of actors is omitted, abstracted and administered in ways that make it challenging to see lived realities that defy manufactured uncertainty, including how gender, differences and inequalities are experienced (Smith, 1974, 1979, 1997). Communication of uncertainty has affected

health advocacy's nature and course, including in the breast cancer movement (Batt, 2017). Communication of uncertainty is used as a strategy at the citizen and state level to shape agency in a favourable way to specific financial interests and curb agency related to health-promoting or prevention activities that would impede profit-making. These ideological influences targeted at curbing systemic and structural risk mitigation strategies draw countermeasures by health advocates, such as implementing the precautionary principle (EEA, 2001).

The precautionary principle, as a risk mitigation strategy, addresses uncertainty. Where primary prevention and the precautionary principle are embraced as tactics in the face of scientific uncertainty, agency is enacted at various levels of the system, from the individual to workplace practices, policy and legislation. Environmental health advocates have long argued for applying the precautionary principle in the face of threats to human health stemming from exposure to pollution and toxins (McArthur, 2020). "The precautionary principle is meant to represent the public good in all decisions made under scientific uncertainty. When there is substantial scientific uncertainty about the risks and benefits of a proposed activity, policy decisions should be made to err on the side of caution with respect to the environment and the health of the public" (Kriebel, Tickner, Epstein, Lemons, Levins, Loechler, Quinn, Rudel, Schettler & Stoto, 2001). In the case of environmental risks for breast cancer, communicating uncertainty while promoting precaution could shift the landscape of women's understandings and for exposure reduction strategies.

As health communications literature brings out, recognizing the discourses operating in cultural and social contexts illuminates crucial influences on understanding health risks. Understanding how individuals conceptualize and behave in the face of risks within the framework of the nested set of relationships they live, work, and play is critical. The individual's influences must be placed in context to grasp why and how individuals respond as they do. Garland's (2002) description is apt:

individuals vary in their propensity to take risks – whether as a result of personal dispositions, cultural bias, past experience, or available security sources – and so do institutions. Individuals and institutions are usually responding to hazards in company with other individuals and institutions whose collective decisions and conduct will affect the risk that any one of them will face. (p.8)

The discourses of risk as reflective of power, context, and social realities operating in the multiple sources of information that are present in the socio-cultural frameworks that women live in (and are sometimes oppressed in) are key to analyzing how breast cancer risk understandings and risk mitigation strategies are constructed in the form of narratives.

### Illness Narratives and Breast Cancer (Counter) Narratives

The literature on illness narratives provides critical ideas in the framework of this study. Analyses of illness narratives stimulate novel ways of translating experience to policy and regulatory strategies and initiatives (Nielsen, 2019). What is foregrounded and backgrounded in breast cancer experiences narratives is insightful for understanding personal and societal priorities. As incorporated into narratives, breast cancer risk perceptions are "based on a variety of factors involving individual experience, cultural beliefs, social practices, attitudes and values" (Davis, 2008). The information incorporated by women into their illness understandings changes at different periods, reinforcing that breast cancer risk understandings are the product of subjects located in specific contexts and conditions (Davis, 2008). The identification of typologies of illness narratives aids in the classification of roles that storytelling can play in the illness experience and related action strategies.

Arthur Frank's illness narrative typologies (1995) have been used to further the understanding of breast cancer stories (Thomas-MacLean, 2004). Frank categorized illness narratives into three main types: *restitution narratives*, *chaos narratives*, and *quest narratives* (Frank, 1995). Illness narratives are therapeutic for the patient, but they also contain a sense of "moral responsibility," which moves beyond the individual's experience to serving social and cultural functions. The method of organizing narratives by typologies based on the content or conceptual underpinning of the narratives, as Frank does, is useful in analyzing how narratives reflect the located, lived experience of the illness narrator.

Narratives of illness experience are both individually and culturally mediated. Early breast cancer culture gave rise to narratives that adopted the pervasive discourse of the individualization of risk. "Dominant ideologies are embedded in accounts of illness and fundamentally shape what are often mistaken to be neutral narratives...dominant ideologies infiltrate representations of cancer and blame people for being sick" (Fosket, Karran & LaFIa, 2002, p. 303). Sweeney describes dominant breast cancer narratives oriented around the biomedical model of disease and individual attribution of risk management while "downplaying social, structural, political, economic and environmental factors that influence the disease (Sweeney, 2014, p. 949). Garrison (2007) reports the widely recognizable war metaphor—battle with breast cancer—often adopted in women's breast cancer narratives, showing the interplay between the individual subject and their socio-cultural context. Though the individual focus on biomedical regimes remains predominant in narratives, some breast cancer activists challenge this (Klawiter, 2004; 2008).

Counter-narratives to the biomedical frame emerged from social movements on breast cancer (Klawiter, 2004; 2008). An intersection of the women's liberation movement, the early breast cancer awareness movement, the breast cancer prevention movement, the environmental breast cancer movement, and the "think before you pink" movement, among others, influenced women's narrative construction of the breast cancer experience (Klawiter 2004). Despite the institutions that exert a heavy individualizing influence, some women have transformed the focus and politicized the disease through collective action (Klawiter, 2008). Breast cancer and other women's health movements serve to challenge assumptions about risk and health as individualized, leading to new conceptualizations, nuanced ways of understanding, and modes of acting that resist biomedical, depoliticized views of health and illness.

Nielsen (2011, 2019) illuminates breast cancer counter-narratives in a form she describes as disruptive breast cancer narratives. Borrowing from Frank's narrative typologies of the illness experience (1995), Nielsen also finds that breast cancer is expressed through narratives that serve social and cultural functions (2019). The breast cancer experience is, at times, *heroicized* or made manifest as an exercise in judging and assigning value or worth to experiences while seeking to restore a sort of moral agency (Nielsen 2019, p. 37). While narratives of heroization are masculine, women

do, at times, adopt these, showing evidence of the dominance of specific narratives and discourses operating in the social world, including the prevalence of patriarchal norms.

Breast cancer counter-narratives are not necessarily antagonistic towards the medical humanities (Nielsen, 2019, p. 40), but illuminate the heterogeneity of illness and health narratives and bring out the legitimacy of varied and disparate stories of health and illness. Being open to the counter-narratives is a critical analytical approach to breast cancer narratives, as a window into women's struggles from the point of view of their own lives, from their location. Support group narratives that tend to foreground a cheerful complacency and are apolitical are disrupted in the narratives Nielsen studied (2011). These narratives are presented as alternatives to the war metaphor and the rhetoric of battle present in breast cancer discourses (Garrison, 2007).

Narratives that investigate agency and power challenge assumptions and enter into critical elements of stories, thereby revealing underlying social and structural contributions to illness experience and understanding. These functions of illness narratives also illuminate oppression (Nielsen, 2019). Women's breast cancer stories bring out how life challenges are taken up by subjects and "provide meaning-making, understanding and narrative coherence in an otherwise chaotic world of illness" (Nielsen, 2019, p. 36). Disruptive breast cancer narratives are critiques of the culture of happiness surrounding breast cancer survivorship and challenge the breast cancer experience's dominant discourses. Narratives of disruption run counter to the homogenous, standard tales of biomedicine and the experience of illness as a moral quest. Importantly, disruptive narratives expose master narratives to a scrutiny of the power dynamics that lie within them.

Narrative as an object of inquiry offers novel insights that push the longstanding trend of narrowing risk to biomedicine's boundaries. Disruptive narratives encompass a wide range of resistances or tensions that work against the tendency to "solidify knowledge" in the biomedical realm (Nielsen, 2019, p. 14). For many patients, biomedical explanations are incomplete accounts of the illness experience, and narratives that resist these tendencies function as contrast and corrective measures to the individualization of the illness onto the body of the person (Foucault, 1973). Social relations, cultural context, and politics—the personal and the structural—become visible in disruptive breast cancer counter-narratives.

### Feminist Perspectives

Feminist research has made significant and essential contributions to social research. These include standpoint theory, intersectionality, experience as knowledge, questions of authority and representation; empathy; identification; colonized, oppressed, subaltern viewpoints; conflicting perceptions, reflexivity, and more (Hesse-Biber, 2012; Kemmis & McTaggart, 2000; Visweswaran, 1997). Feminist theory locates women as embodied subjects in contexts shaped by patriarchy, race, and ability (Hesse-Bieber, 2012). Feminist health researchers reinforce that health is "embedded in communities, not just in women's individual bodies" (Ruzek, Olesen & Clarke, 1997, p.13).

Situating women as subjects in their social contexts, with their perspective as the central starting point, is an essential contribution of feminist literature to the study

71

of women's understanding of environmental risks for breast cancer. Gender is a critical entry point into systems of meaning and analyses of understandings of power as part of the socio-cultural landscape (Visweswaran, 1997). Feminist analyses engage with critical understandings of the world, with a systematicity that explores assumptions and considers particularities (Mascia-Lees, Sharpe & Cohen, 1989). Feminist research approaches aim to "ameliorate harms and disadvantages that women experience" (Hesse-Biber, 2012). When conducted from a feminist perspective, women's health studies, inclusive of environmental risks for breast cancer, challenge conventionally male-oriented knowledge production about women's health, and can "demonstrate point by point, the deficiencies of alternative explanations" (Hawkesworth, 2012, p. 114). Women are often "made invisible as subjects in their own lives and experiences" (Holstein & Gubrium, 1995, 24), but through feminist research, examining women's narratives of experience uncovers and exposes their validity to health understandings.

Feminist research fosters applying a social lens that connects the personal to the social, locating individuals as situated and embedded in particular contexts. A social lens on breast cancer provides a view of the conditions of women's lives as they contribute to and shape the disease. Women's "race and ethnicity, education and income resources, housing and neighbourhoods, social relationships and support, and other experiences and circumstances" enter into social understandings of breast cancer (Ferguson & Kasper, 2002, p. 4). Feminist, social insights of breast cancer are crucial, having "revealed the biases of male dominance, hierarchy, and overreliance on the biomedical model that distort basic scientific research" (Rosser, 2002, p. 266). Traditional male dominance comprises social meanings embedded in women's breast cancer experiences (Rosenbaum & Roos, 2002). These distortions impact the understanding of breast cancer risk factors and affect primary prevention efforts, screening, detection, and breast cancer treatment.

Feminist perspectives that situate the individual in the social context produce counter perspectives to the biomedical and other dominant perspectives that treat the body as separate and as independent of the social. Sue V. Rosser's research reveals "not surprisingly, controversies in breast cancer research demonstrate many of the problems that women's health, in general, has suffered at the hands of a maledominated, hierarchical health system based on a biomedical model of medicine" (Rosser, 2002, p. 246). The traditional biomedical focus prioritizes anatomy, physiology, causes at the cellular, hormonal, and genetic levels while at the same time omits behavioural, social and environmental contributions to breast cancer. Disregarding social and environmental factors limits the scope of research attention and funding of these factors and failures at the legislative, regulatory, and policy levels, compounded by the fact that men's breast cancer incidence is much lower than women.

Men's health problems have, generally and historically, tended to garner greater attention and funding than those experienced by women. Women's workplace exposure is one of the gaps produced by this phenomenon. "Links between breast cancer and workplace exposures to carcinogens are not well understood because, historically, women workers have not been the objects of study in occupational health investigations" (Steingraber, 2002, p. 279). Given the paucity of research on women's health and the social context of breast cancer, in particular where women workers and breast cancer risks are concerned, a corresponding gap in women's understandings of risks for breast cancer within these same social and environmental contexts is to be expected. Applying feminist literature insights to this study offers an entrée into the investigation that can address the gendered gaps in breast cancer study, especially in working environments where breast cancer risks are present.

### Locating the Environment in Breast Cancer Risk Perception

Illness and disease prevention communications are often based on the premise that risk factors can be changed or controlled (Goodman & Samet, 2006). Some risk factors for cancer at the individual level are generally considered unmodifiable, including sex, age, genetics, and family history. Modifiable risk factors for cancer tend to be dichotomized as either lifestyle or environmental, with lifestyle factors focusing on individual behaviours, such as smoking, diet, and exercise, which are presumed to be modifiable (Probst-Hensch & Künzli, 2012). Lifestyle implies individual volition, whereas environmental risk factors usually refer to involuntary exposures to cancercausing agents. In other words, environmental risk factors are largely beyond the control of the individual (White, Peipins, Watson, Trivers, Holman, & Rodriguez, 2013). Whether or how women understand these distinctions is essential from the perspective of the construction of breast cancer risk understandings and associated risk mitigation strategies.

The prevailing treatment of breast cancer risk factors as fundamentally and individually modifiable leads to the portrayal and understanding of the disease as personal rather than social. The omission of crucial risk factors occurs when there is a failure to consider the social conditions for breast cancer. Social factors including food quality, associations between pesticides and other toxins with breast cancer,

socioeconomic inequalities, and other social factors including political, economic, and environmental risk factors are ignored while emphasizing exercise and personal choice (Fosket, Karran & LaFIa, 2002). The absence of societal and social structures as contributors to breast cancer risk, including environmental factors, leads to the issue of breast cancer being "depoliticized and decontextualized" (Fosket, Karran & LaFIa, 2002, p. 320).

Ann Robertson (2000) investigated the influence of political discourse on the experience of breast cancer risk. The women Robertson interviewed tended to organize perceptions of breast cancer risk in terms of personal risk factors and agency at the individual level to mitigate them. Robertson observed that, although they spoke about environmental problems, "not one of them talked in terms of collective solutions at the social, political and economic levels, such as lobbying for stricter environmental controls or food regulation" (2000, p. 227). Just as in studies on media and medical discourses, individualization of the risk to the subject was identified in Robertson's study, framed within a broader neo-liberal paradigm of responsibilizing the individual. Women were aware of environmental risks, yet they still created individualized strategies and protections rooted personally. In other words, their strategies for environmental risk mitigation were consistent with individualized discourses that dominate breast cancer messaging while missing structural and systemic solutions where controls on environmental exposures should be applied.

Rice, Rice, Brandt, Hardin, Ingram, and Wilson (2015) studied cancer risk perceptions, including neighbourhood environmental risks. They report that

perceptions of breast cancer risk from environmental sources were shaped by social determinants (including race and ethnicity and social and economic factors) along with personal or family experiences (Rice et al., 2015). Health psychology researchers, Volkman and Silk (2008), investigated perceptions of environmental risk for breast cancer among adolescents and their mothers in focus groups. Their study found that, among their participants, the ambiguity and confusion about environmental risk factors for breast cancer contributed to uncertainty about how to behave and respond to environmental risk messaging (Volkman & Silk, 2008). Similarly, Atkin and Smith (2010) found significant weaknesses and inadequate information about environmental contaminants and preventive behaviours in messaging for both specialized and public audiences. Their findings led to the creation of recommendations for improved communications practices for environmental risk reduction.

The absence of research focused on environmental factors is problematic in that "continuing to focus on the cellular, hormonal and genetic causes represent a reductionist approach to the problem" (Rosser, 2002, p. 266). The findings of a study using Kleinman's theory of medical and cultural systems (1978) to understand how residents of the Aamjiwnaang First Nation near Sarnia, Ontario, viewed environmental threats to their health reinforce social factors' importance and situatedness to the perceptions of environmental health risk by participants. Residents struggled with balancing cultural, spiritual and historical understandings of identity connected to the land with the knowledge of environmental health threats resulting from air, water, and soil contamination from nearby petrochemical industries. The people of Aamjiwnaang interpreted these risks and potential responses by using traditional or folkways of knowing, community ties, notions of family, and cultural knowledge systems (Bedeau, 2006). The findings of these studies speak to the importance of local narratives in addition to broader societal narratives.

The particularities of local environments enhance insights about the conditions surrounding the construction and understanding of health risk narratives. Occupational environments must be a component of the communications around environmental risks for breast cancer as well, and this begins with researching women in their workplace environments. The dedicated focus on interrogating women as subjects in their locations in this study, particularly in a work environment with known breast carcinogens, is a step towards rectifying this gap.

# Integrating the Literature Towards the Study Objectives

The main conceptual ideas elucidated in the literature discussed coalesce in a 2018 review of sociological literature on cancer. Kerr, Ross, Jacques and Cunningham-Burley (2018) identified three main themes over the period 2007-2017: the social and biographical context of cancer identification, the individualization of risk and responsibility, and structural inequalities. Kerr et al. identified a tendency to study cancer as biomedical, noting that sociological studies have both mirrored and challenged this (Kerr, Ross, Jacques & Cunningham-Burley, 2018). Studies took "the individual life-world as the point of departure" (Kerr, Ross, Jacques & Cunningham-Burley, 2018, p. 558), including focusing on how individuals interpret and respond to cancer risk and prevention strategies within their social locations (Kerr, Ross, Jacques & Cunningham-Burley, 2018).

The 2018 Kerr et al. review also noted numerous studies (Armstrong & Murphy, 2008; Keeley et al., 2009; Nekhlyudov et al., 2009; White et al., 2012) that found women incorporated biography and lay knowledge to inform their decisions about cancer screening and care (Kerr, Ross, Jacques & Cunningham-Burley, 2018). This approach sometimes leads to fatalistic perspectives in dealing with cancer risk uncertainties. This study seeks to understand agency in response to breast cancer risk knowledge, and Kerr et al.'s finding that fatalism influences action alerts us to the possibility that not exercising agency is also an agentic response among the possibilities adopted by women.

Kerr et al. suggest "we extend our understanding of innovations in the fields of cancer research to take better account of these wider social and cultural innovations [beyond biomedical], together with patients', activists' and sociologists' contributions therein" (Kerr, Ross, Jacques & Cunningham-Burley, 2018, p. 552). Moving beyond the technological and regulatory process leads to a more comprehensive account of cancer that considers "identification and distribution of power and status in the cancer field – across research, treatment and cultural realms...beyond the limited scope offered by the identity politics of consumer society" (Kerr, Ross, Jacques & Cunningham-Burley, 2018, p. 564). Situating breast cancer risk research in a framework that accounts for social and cultural factors, and investigating agency related to these as this dissertation contributes to increased research directed at social, behavioural, and environmental causes of breast cancer, and the conditions to "initiate the steps needed to correct overreliance on the biomedical model" (Rosser, 2002, p. 267). Examining women's narratives of breast cancer risk and related environmental

risk mitigation strategies contribute to addressing gaps, as noted in the literature. With the study located in the relevant literature and concepts, the next chapter outlines the study methodology, outlining the qualitative research design steps for the project, beginning with a description of the study context.

### **CHAPTER FOUR**

### **Research Design and Methodological Approach**

The questions 1) How do women who work (or have worked) in an environment identified as posing an increased risk of breast cancer construct narratives and understandings of their breast cancer risks? 2) How do women place the environment in their narratives? and 3) How do these women perceive and exercise agency in the context of those risks? were answered using a qualitative research design, consisting of individual, in-depth narrative interviews using open-ended questions with 25 women who worked at the Ambassador Bridge, an environment with identified breast carcinogens. The theoretical framework—comprised of Kleinman's approach to the medical system as a cultural system (1978), standpoint theory (Harding, 1984, Smith, 1974, 1979, 1997; Collins, 1986, 1990) and a socioecological framework (Bronfenbrenner, 1977; Schettler, 2015' CHE 2020)—as outlined in Chapter Two served as a guide for theme, category and code identification, and for analysis of the narratives.

### The value of qualitative design for this research

A qualitative study design is appropriate for investigating women's understanding of breast cancer and environmental exposures. Qualitative sociology's findings are insightful, persuasive, and aim to see social settings in their complexity, including "the details, the variations, the ambiguities, the contradictions, and the choices that people or groups make" (Goodwin & Horowitz, 2002, p. 45). Qualitative methodologies provide contextual information and produce different lenses on the social realities that make societal phenomena understandable (Alasuutari, 2010). Through different lenses, often more specific and local, qualitative methods can facilitate considering factors from the micro to the macro levels of societies. Concerning health, making the connection from micro to macro—the individual to the structure—is particularly beneficial for the specificity that can be garnered through qualitative research methods. As noted by Brown (2003), these specificities are of particular importance to community-based environmental health research.

Qualitative methods in environmental health studies give voice to otherwise unheard individuals and organizations. Environmental health effects include not only illness and disease but also the embodied experiences of health. Following a qualitative research process, the complexities of lay knowledge provided through health studies can facilitate understanding the experiences and knowledge of those studied towards action on environmental health problems (Brown, 2003).

A foundational idea for this research design is that breast cancer "is not only a disease of abnormal cells but also of communities that we create and live in" (Schettler, 2014, p.7). Schettler's approach moves the individual's gaze to the design of communities, the specific sites where conditions for breast cancer development may be present. The research was designed to capture the individual perspective in their social, geographical, community, and workplace contexts. Socially located considerations were incorporated in the research design, including the research and interview questions (see Appendix A) and the complementary open-ended, dialogical approach to the interviews.

The study's interview approach intentionally invited personal narratives that would situate the subject and elicit understandings derived from social locations, including the broader community and society more generally. The approach lent itself to capturing descriptions linking the micro-settings of women's lives and perceptions to the macrostructures of class, economics, politics, governance, and gender inequalities, among others (Wacquant, 2002, p. 1499). Capturing contextual and historical specificity are essential components in research design (Carroll, 2004; Charmaz, 2006, 2011; Chase, 2008; Creswell, 2011 and Hesse-Biber, 2013) to garner "an understanding of the intimate realities of ourselves in connection with larger social realities" (Carroll, 2004, p. 350).

Women's understandings of health risks are constructed in a complex web of cultural and social relations that reflect structural, ideological, relational and mediated influences. To study these understandings requires an approach that accounts for the complexity and diversity of information sources, including knowledge from multiple disciplines and convergence of perspectives and knowledge of the researcher and participants. The researcher becomes a bricoleur, connecting and assembling various knowledge pieces (Kincheloe & McLaren, 2008). The bricolage approach can include a critical lens, pertinent to exploring the problem of breast cancer as socially constructed (Kincheloe & McLaren, 2008, p. 405). To understand how community, structural and ideological influences (the cultural experience) come to bear on breast cancer risk understandings, the study was designed to "pry open and reconsider the thinking hidden within the black box of biomedicine" and "push for a broader researcher vision" (Burawoy et al., 2000, p. 304).

Care in interpretation is one of the challenges of analyzing such a research design given the potential for heterogeneity (i.e., disparate and diverse data) (Feilzer,

2010, p. 13), and is the task of the bricoleur (Lincoln, Lynham & Guba, 2011). Theoretical and conceptual choices are critical to methodological choices, coming together to analyze the depth and unique features of stories and how they may be "linked to other, perhaps generalizable stories" (Goodwin & Horowitz, 2002, p. 43).

# Feminist Perspective Informing Methodological Approach

The qualitative study design for this research is positioned within a critical, feminist framework. In particular, a critique of women's individual responsibilization for health decisions under neoliberalism informs the approach. The dominant social and cultural framing of breast cancer risks as predominantly personal creates a gap where environmental exposures, especially those which are primarily involuntary, are concerned.

This study's methodological approach includes open-ended questions about agency and control over breast cancer risks, seeking to understand these issues through women's voices and standpoints. Open-ended narrative interviews with a few planned interview questions and probes construct the space where women's voices are valued and prioritized and where their knowledge is the basis for the findings. The theoretical framework for the analysis is decidedly feminist. The adoption of feminist standpoint to the theoretical and analytical framework, with the recognition that the women's situated, located, lived experiences provide particular kinds of knowledge otherwise ignored, subordinated or omitted, grounds the feminist methodological approach.

Standpoint feminism locates women within their context, appreciating how their understandings are suppressed by ruling relations and allows examination of uncertainties, situations, external factors, and marginalization of experiences through ideological understandings. Women's vast knowledge and interpretations of the locally produced understanding sheds light on the ways in which risks are manufactured by society and, therefore, should incorporate women's subjectivities. Relevant risk mitigation strategies cannot challenge specific risk contexts' pervasiveness without including women's perspectives.

The feminist standpoint fosters investigation of context's ruling relations by discovering the thoughts that people have and which structure the world they live in through their words (Smith, 2005). This approach establishes the subject as the knower and creator of contextually specific knowledge (Smith, 2005). This framework provides an entrée into the specific settings, practices, and relations that produce, coordinate, and construct risk perceptions by the women interviewed. "Talk and text," as seen through women's consciousness and subject location as evident in their stories, reveal breast cancer risk understandings when examined through narrative and discourse analysis (Smith, 2005, p.76).

Narratives that challenge hegemonic ways of meaning-making for breast cancer, such as the responsibilization of the individual woman for their breast cancer, allow women to act as "agents of meaning-making in the context of unequal power relationships" (Porroche-Escudero, 2011, p. 19). Challenging narratives also shed light on the structural forces that contribute to breast cancer risk, bringing to light aspects of the breast cancer experience that the dominant discourses omit or relegate to the margins. Narratives can reveal "underlying power dynamics and normative gender constructions on women in relation to illness and narrative" (Nielsen, 2019, p. 44). Through women's standpoint, investigating ruling relations through narratives allows for understandings of the structures of lived experience and knowledge of women, establishing the subject as the knower and creator of social knowledge (Smith, 2005). Standpoint centres women's knowledge production, showing how "culture has influenced what we know and do not know about breast cancer" (Ferguson & Kasper, 2002, p. 2) and how society and social institutions have shaped the experiences of the disease.

### Methodology

#### Narrative Interviewing: Women as Authoritative Subjects

Through the theoretical lens of subject location and using women's standpoint, narrative analysis directs the project's methodological approach. For the purposes of this research, "narrative" refers to the stories the 25 women interviewees tell of their understandings of breast cancer risk. Discourses within those narratives contribute to how those stories are told, including the language used, the arguments made, the references applied, and the frameworks for understanding in constructing the stories (Hall, 1993; Chalaby, 1996). The study's data collection method centres on narrative interviewing for its ability to explore words and discourse, social and historical understandings, actions, and conflicts (Tanggaard, 2009). Narrative interviews aimed at analyzing women's understandings of breast cancer risks can illustrate "how language makes people and produces social life and for opening up public discussions (Tanggaard, 2009, p.1513).

Narrative analysis takes as its object of investigation the story itself and illuminates the storyteller's personal perspective. In the case of this study, the women

interviewed narrated their perspectives as situated in their social contexts on breast cancer risks, inclusive of their ideas on individual and collective action, while incorporating a multiplicity of health and breast cancer discourses. Narrative interviews and their analysis illustrate how moral ordering and subject priorities figure into the construction of the narratives as reflections of knowledge rooted in the subject's story (Fontana & Frey, 2005; Kleinman, 2007; Chase, 2008).

When taken as a theoretical standpoint, interviews provide a window on the world through which social analysis can be coherently and rigorously realized (Holstein & Gubrium, 1995). Interviews allow the exploration, "through words and discourse, peoples' socially and historically embedded modes of understanding and acting, and also the possible 'conflicts' between different types of acting and understanding" (Tanggaard, 2009, p. 1513). Investigating women's understanding of breast cancer risk through narrative interviews is a social interaction with a "combination of observation, empathetic sensitivity, and intellectual judgment" (Fontana & Frey, 2005, p.703) can elicit in-depth insights as viewed through the lens of the subject.

Appreciating the interview as a dialogical context is particularly salient for understanding women's knowledge of breast cancer risks. While the interview guide outlines the specific questions corresponding to the research objectives, recognizing the interaction with the interviewee as an exchange wherein both the researcher and the participant are producing knowledge is fundamental. Embracing interviews' dialogical nature through an in-depth exploration of breast cancer risk understandings captures the subjects' experiences and expertise. These exchanges elicit descriptions and reflections from the person interviewed that everyday day life rarely produces. The interviewer is positioned to "listen, to observe with sensitivity, and to encourage the person to respond...the participant does most of the talking" (Charmaz, 2006, p. 25-26), allowing for their narrative constructed in response to the interviewer's questions to emerge. The key to this careful interchange is recognizing that interviews produce "dissenting opinion, diverse discourses, and personal narratives" (Tanggaard, 2009, p. 1513) through dialogue. Being open and attuned to the potential for either homogeneity or multiplicity is vital to both eliciting authentic narratives and the rigorous analysis of them.

Keeping with a feminist standpoint and considerations of gender inequality, narrative interviews with women about their experiences and understandings of breast cancer risk can begin to remediate gender biases of science, where traditionally male exposures and experiences have been treated as though they are equivalent to women's. Women's bodies, women's workplaces, women's jobs, women's life experiences, and gender constructions are meaningfully different from men's in many ways. Women and men in the workplace not only have "different biology, but they also have different seniority, average age, task assignments, work techniques, and lives outside work" (Messing, 1998, p. 22). In occupational health research, these differences have often been overlooked. Gathering women's health experiences through narrative interviews, including their life and work stories, provides insights for the social and natural sciences where they have traditionally been the purview of men, dominating what we know about health risks. Discourses of breast cancer that focus on individual women's bodies, behaviours and choices as risky remove them from the communities, institutions and societies of their experiences, depoliticizing and decontextualizing them (Fosket, Karran & LaFIa, 2002). However, the standpoint captures the marginalization that results from breast cancer's dominant discourses—recognizing women's experience as political illustrates that breast cancer is a personal problem and primarily an experience constructed through social context. The question of agency from women's standpoint is uncovered and analyzed, providing women-centred, less-oppressive ways of approaching environmental breast cancer risks and mitigation strategies.

Beginning with women's subject location using the narrative interviewing method challenges dominant knowledge systems that claim to portray women's experience. Women's understandings constructed through their knowledge and perspectives on ruling relations, power, conflict, and everyday practices, and situated in an ecological framework, apprehend the nested set of relationships women live in. In this framework, women's narratives work to uncover these interrelationships' problematic nature as they affect health risk. With the focus on women's location, context is recognized as influencing interpretations. What women know, what narratives they incorporate, and their narratives' specificities related to agency and power are visible from the subject's position. The approach opens the door for the consideration of different knowledge systems, creating the opportunity for feminist knowledge production.

# Narrative Analysis Through Theory

Narratives illustrate how women work to convert the complexity of health understandings and uncertainty about breast cancer risk into understandable, manageable, subjective understandings. Though women incorporate objective realities into narratives, such as knowledge of genetics, lifestyle, and environmental risks, seeing the narratives through a socioecological lens facilitates explaining how knowledge systems are utilized, how certain domains are privileged over others, and how women make sense of breast cancer risks. The fundamental approach to narrative analysis through theory is that the experience of breast cancer risk is a complex relationship between the individual and the broader social, political, and discursive contexts in which they are lived. Understandings of illness are both cultural and social. They are "not simply systems of meaning and behavioural norms, but those meanings and norms are attached to particular social relationships and institutional settings" (Kleinman, 1978, p. 85).

Narratives are emblematic of the complexities of the social world in which they are rooted and can serve the function of "providing personally and socially meaningful explanations" in the management of health (Kleinman, 1978, p. 87). Narratives of risk can contribute knowledge to understanding along the health system continuum, from prevention to risk to illness, diagnosis, and treatment. Narratives acknowledging structural relationships and institutional factors bring into focus the full experience of health while including enacting or strategizing agency opportunities within a socioecological framework. As a result, an analysis of how women understand and integrate environmental knowledge within their narratives facilitates new and better breast cancer risk control approaches. Controls over risk include knowledge translation strategies, knowledge mobilization, regulatory and policy modification and creation, risk mitigation at the individual and collective level, and setting priorities for future research investment.

### Discourse Analysis as a Component of Narrative Analysis

Analyzing discourse works on the assumption that language is a form of microlevel representation of social life, interconnected with and related to it "so that social analysis and research always have to take account of language" (Fairclough, 2003, p. 2). Discourse analysis brings out pieces of the complex puzzle of human meaningmaking, wherein meanings shift, change, and resist. The narrative analysis method allows for a sophisticated understanding of how language and discourse make meaning in social life. Analysis of discourses operating through a personal narrative facilitates locating a "basis for perceiving or interpreting a particular phenomenon" (Tanggaard, 2009, p. 1511). As a part of larger narratives, discourse analysis sees communicative events in broad contextual terms and the framework of sociopolitical issues (Van Dijk, 2006, p. 160). Investigating narratives using discourse analysis explores how women and other marginalized groups produce disruptive or resistant narratives that shift knowledge, ideas and subjectivities and counter or challenge hegemonic discourses.

Discourses operating in breast cancer risk narratives are essential components of broader narratives constructed by subjects. Analysis of breast cancer risk stories inclusive of dominant and other discourses advances disciplinary knowledge, garners structural understandings of the issue, identifies sites of political and other forms of agency, and fills in gaps of the tendency to present the issue centred in a biomedical frame. Analysis of discourses in breast cancer risk narratives sheds light on marginalized discourses of health and medicine and offers strategies for influencing policy, regulatory strategies, and other initiatives (Nielsen, 2019).

# **Study Context**

The primary sample comprises women who currently work or have worked at the Ambassador Bridge in Windsor, Ontario, Canada. The bridge is an appropriate site for research into understandings of breast cancer risks as research has demonstrated elevated risk for breast cancer among women working or living where there are high volumes of air pollution, including vehicular traffic (Brophy et al., 2012; Crouse et al., 2010; Gray et al., 2017; Hystad et al., 2014; Luginaah et al., 2012; Mordukhovich et al., 2016; Pan et al., 2011; Schettler, 2014; Villeneuve et al., 2017; Wu et al., 2016). Studies also increasingly connect shift work with breast cancer risk (IARC, 2010; Brudnowska, 2011), both of which are part of the Bridge's working conditions.

Working at the Ambassador Bridge complex might in itself provide some awareness of environmental risks for breast cancer given that there have been numerous cases (anecdotally reported by the union to be anywhere from 10 to upwards of 20 or more cases) of breast cancer among workers in the past two decades. There is an ongoing Workplace Safety and Insurance Board (WSIB) claim for breast cancer by a former CBSA employee, part of a broader struggle to recognize the association between exposures at work and breast cancer (Gilbertson & Brophy, 2018). Additionally, the Customs and Immigration Union (CIU) has actively raised concerns about these environmental exposures. Given the local media attention on breast cancer in 2006 (Brophy et al., 2006), and more recently in 2012 with the publication of research on occupational risks for breast cancer (Brophy et al., 2012). As well, with the attention to the cases of breast cancer among these workers, there may be a heightened consciousness on the part of women working at the Ambassador Bridge about the suspected association between their workplace and breast cancer.

# **Data Sources**

Interviews are the study's primary data source (See Appendix A, Interview Guide for interview questions and probes). Following each interview transcription, a summary was created, including all relevant participant characteristics, a brief synopsis of the topics covered, prevalent themes in the interview, and notable quotes from the interview. Interviewees were provided with a copy of their summary as a member check and affirmed that what was recorded accurately reflected their narrative. In addition to the interviews, meetings were held with other key informants (DiCiccio-Bloom & Crabtree, 2006). These individuals were knowledgeable about the history, working conditions, health and safety issues, workplace characteristics at the Ambassador Bridge, and one former employee who filed a compensation claim with the Ontario Workplace Safety and Insurance Board (WSIB) after being diagnosed with breast cancer.

#### **Recruitment of Interview Sample**

There were two phases of recruitment. Initial access to women in the workplace was secured through connections already made before the formal research project. These included present-day employees, a past employee who sought to establish a workplace compensation claim for her diagnoses of breast cancer, as well as members of the union health and safety committee who expressed an interest in facilitating this research effort.

Recruitment materials were created and printed and distributed to known contacts, union representatives and eventually to all interviewees (See Appendix C). Recruitment materials were sent to workers/former workers at the Ambassador Bridge with whom I was already familiar. One woman contacted me, and she became the first participant to be interviewed. She was provided additional recruitment materials in the form of the study flyer and my contact cards to pass along to potential future participants.

After several weeks had passed without contact from any women willing to participate, a media release about the study was distributed (see Appendix B). The local newspaper, *The Windsor Star*, contacted me in response to the media release and published a story and a video on the study with a recruitment appeal. Within hours of publication on-line (Hill, 2018), potential participants contacted me and scheduled interviews. Ultimately, more than 50 people contacted me, and of those, 25 were interviewed. The remaining 25 participants were asked to provide contact information for possible future research and so that I could share the study results with them upon completion.

#### **Sample Participants**

The sample is comprised of 25 women who work or have worked at facilities at the Ambassador Bridge. The participants were women aged from the twenties to 60s, with all but two participants aged 30 or older. Nearly three-quarters of the women were born in Windsor-Essex County, and all but two resided at the time of the

93

interview in Windsor-Essex County. All women had some post-secondary education, with all but one completing a university or college degree. About 30% of the women also had post-graduate education.

Of the 25 participants, 80% were employed at the Ambassador Bridge by the Federal Government, now called the Canadian Border Services Agency (CBSA). The remaining five women worked either for the privately-owned company operating the Ambassador Bridge, a customs brokerage, or the Ambassador Bridge Duty-Free Shop. The Duty-Free Shop and customs brokerage employees had the shortest tenure, having worked at the bridge facility for less than two years, while three-quarters of the women worked ten years or more, with nearly a quarter of them having worked 31 years or more for CBSA. At the time of their interviews, more than half of the women were either retired from CBSA or still working at the Bridge, while the others were working elsewhere. Of note, the women employed by CBSA were members of the Customs and Immigration Union (CIU), a component of the Public Service Alliance of Canada (PSAC). Eighteen of the participants were diagnosed with breast cancer. All but three women were aware of other women at the Bridge with breast cancer, some saying they knew only one or two, while others said they were aware of up to nearly 30 other women.

#### **Data Collection Procedures**

Data collection consisted mainly of 27 interviews (2 ineligible) from April 2018 to the end of June 2018. The interviews took place at locations chosen by the interviewees. Most selected The Muse, a graduate student lounge in the Department of Sociology, Anthropology and Criminology at the University of Windsor, a private, closed, secure meeting space. Two interviews were conducted in participants' homes, two were conducted in my home, and one was conducted at a public café.

Interviews began with introductions and an explanation of the study's purpose and a review of the procedures related to the ethical conduct of research (See Appendix D). Any questions the participant had were answered at this time. Following consent, the digital recorder was turned on, and the interview proceeded following the interview guide. As is consistent with the iterative nature of the planned research and elicit narratives, the interview guide only included a few open-ended questions. Probing questions were used when necessary, in keeping with the research area and the theoretical framework. Handwritten notes were taken during the interview as a supplement and back up to the digital audio recording. Interviews lasted approximately one and a half to three and a half hours.

When the interview was completed, the interviewee was paid a \$25 honorarium and costs of parking. Interviewees were asked if they would be willing to share information on the project with other current or past employees with the hopes of securing additional interview subjects, and each was given copies of the recruitment flyer and business card. Post-reflection interview memos were compiled along with notes on any relevant thematic or theoretical connections were made following the completion of each interview.

Interview recordings were uploaded to a password-protected computer and a password-protected external drive. The interview recordings were transcribed by a transcriptionist and eventually uploaded to Dedoose, a web-based data analysis programme (dedoose.com). Interview participants were assigned a pseudonym for additional confidentiality. Participants' names and other identifiers were kept separate from the interview transcripts, and a number assigned to the interview transcript to correspond with each participant.

As described above in data sources, a summary of each interview was prepared and sent to each interviewee. Summaries were delivered in the format each interviewee requested when contacted about the completed summary. Some summaries were delivered in person, some by regular mail, and others by e-mail. Interviewees were asked to review the summary, authorize or decline the use of their interview in the study, and provide any additional comments on the topics covered in the interview. Participants were reminded that this was the last point at which they may withdraw and were asked to contact the researcher within two weeks of receiving the summary with their decision. Some participants followed up with comments, two with minor changes to quoted excerpts<sup>5</sup>, and many made no further contact. None of the participants indicated a desire to withdraw. The preparation and delivery of the formal summaries for the participants was carried out from November 2018 through April 2019.

Notes and memos were compiled on an ongoing basis to facilitate the development of codes and relevant themes as the narratives were collected (Lofland & Lofland, 1995; Charmaz 2006). These contributed to the use of probing questions, used to facilitate more in-depth discussion where warranted within interviews. The process was an iterative one, with the interviews conducted and questions asked of each

<sup>&</sup>lt;sup>5</sup> Some interview excerpts included in this dissertation have been edited for reading clarity.

participant, handwritten notes and memos created following each interview, coding transcripts for themes and concepts, and analytical maps created (Neale, 2016).

Before beginning the population sample recruitment, I met with several individuals who had particular and specialized knowledge of my research topic. I initiated contact with these individuals in both an effort to garner contextual and background understanding of the "problem" of breast cancer among women at the Ambassador Bridge as well as to facilitate the recruitment process (Clifford, 1983). On a few occasions, I met with and consulted with one of the expert witnesses for the compensation hearing for the woman who filed a WSIB claim for breast cancer and with another researcher who consulted on and provided evidence for the compensation case. I also met with and spoke at length with a former union health and safety representative for a more detailed description of the workplace and the overall health and safety context, including breast cancers among the workers.

I organized a group meeting of the two researchers mentioned above, an additional researcher widely published on occupational breast cancer, a current CBSA worker, and a CIU union representative both for their insights on the context of the women in their workplace and institutional settings, as well as any contributions they could make in facilitating recruitment efforts. I had a separate meeting with a former worker and a breast cancer survivor. These meetings established relationships with people in or connected with the group of women I would be recruiting to interview for this study. The meetings also provided information about the work environment, the social, political, economic, and historical context of work at the bridge and the issue of breast cancer, in particular as it relates to the knowledge of breast cancer risks and environments.

Once recruitment and interviewing began, I was contacted by people who were ineligible to be formal participants as part of my sample (i.e., community members with concern about environmental links to breast cancer in the community around the bridge; women with breast cancer but no history of working at the bridge, men who work at the bridge). I interviewed two individuals who contacted me after seeing the information on my study and wanted to contribute. One was a resident and worker in the bridge vicinity and was involved in community health issues in a local organization. The other was a woman who worked near the bridge for many years and was undergoing breast cancer treatment. The information garnered from these individuals provided further context and understanding of the stories told by the women who worked at the bridge. These early meetings preceded my formal interviews for the study, giving preliminary clues about some of the findings that I identified later as the interviews unfolded.

## **Data Analysis**

Narrative analysis of the interviews through the theoretical framework lens, centring subject location and knowledge, directed the analytical approach for this project. Individual, in-depth narrative interviews were the primary data source for analysis. Narrative refers to the women's personal stories of their understandings of breast cancer risk from their standpoint. Narratives illustrate how women translate the complexity of understandings about breast cancer risk into manageable, subjective knowledge. Exploration of the words and discourses in the narratives reveal how language produces social understandings of the phenomenon of breast cancer, including social and historical conflicts.

The primary data source was information gathered in the interviews. The narratives produced in the interview were analyzed iteratively through memoing, sorting, diagramming, coding and integration, making theoretical links throughout (Charmaz, 2006). Coupled with the theoretical framework, the interview data—the women's narratives—were analyzed to describe, explain and represent the subject matter as identified in the narratives in response to the study and research questions (Wacquant, 2002, p. 1524; Wolf, 2010, p. 147). The fundamental approach to narrative analysis through the theoretical and methodological framework is seeing the experience of breast cancer risk as a complicated relationship between the individual and broader social, political and discursive lived contexts. The presence of germane components and concepts in the narratives are made visible by exploring how and why women incorporate certain objective realities into their subjective narratives.

The data analysis process was also an iterative process, beginning with conducting interviews through note-taking, memoing, transcription of the recorded interviews, and the creation of individual interview summaries, the analysis was an ongoing, continuous process (Charmaz, 2006). Handwritten notes taken during the interviews, post-interview reflection memos, memos made throughout the interviewing period, notes on thematic and theoretical insights, and unexpected information garnered from the interviews were all sources explored (Lofland & Lofland, 1995; Charmaz, 2006). Interviewing, note-taking, memoing, diagramming, making connections, linking with theory, developing themes, categories and codes and mapping these connections were repeatedly, continually and reflexively examining the findings and insights through the overarching research questions. A more in-depth analysis of the narratives was undertaken by identifying themes related to the study questions, common themes identified throughout interviewing, and identifying, organizing and mapping concepts and categories and their relations (Lofland & Lofland, 1995; Charmaz 2006).

The process of identifying themes, categories and codes was derived through the writing of post-interview synopses of the narratives to summarize each individual woman's 'story' (Charmaz, 2006; Neale, 2016). Thematic and categorical memos on any initial analytical insights from the stories were made post-interview (Charmaz, 2006; Neale, 2016). The post-interview memos also assisted in conducting subsequent interviews. The incorporation of relevant probes where appropriate allowed for any new issues or themes that emerged in early interviews to be addressed in later interviews (Lofland & Lofland, 1995; Charmaz 2006).

Narratives were examined and analyzed at the word, phrase, sentence, and overall narrative level (Huckin, 1997; Charmaz, 2006). The examination and analytic process produced the identification of pertinent discourses within the narratives (the pertinence of discourses relates to the description and discussion of breast cancer discourses and representations in Chapter 3). As conducted through interviewing and memoing, the iterative analysis process facilitated what would ultimately lead to the theme, category, code and concept and narrative typology identification.

As they connected with the central research questions (see Figure 3) the women's responses produced the main themes of analysis, with three overarching narrative categories identified: risk, agency and power (See Figure 4). Identifying themes produced an entrée into understanding the lived experience of breast cancer risk characterized in the participants' stories.

Figure 3: Theme, Category, Coding and Analysis Guide: The Research Questions

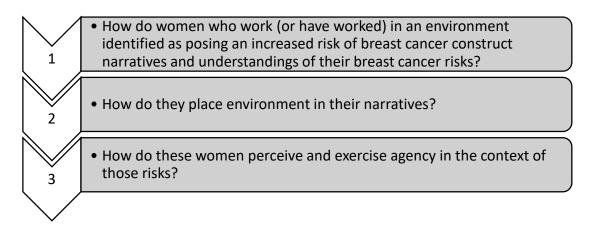
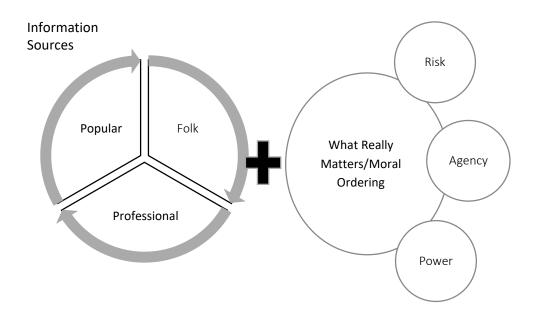


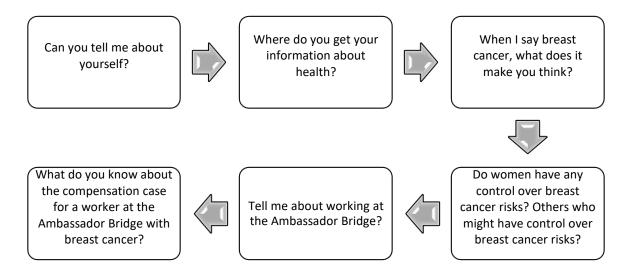
Figure 4: Theme, Category, Coding and Analysis: Theme Identification



The analysis was further organized around the six main interview questions (see Figure 5)

5).

Figure 5: Theme, Category, Coding and Analysis Guide: The Interview Questions



Sets of knowledge, information sources (i.e. personal, biomedical, academic, experiential, etc.), risk discourses, discussions of control and power disparities were critical elements incorporated into the development of themes, categories and codes. Women's standpoint, moral ordering and action approaches were encapsulated in the narratives. The relationships between all knowledge categories contributed to code and category development and the continuing analysis (see Figure 6).

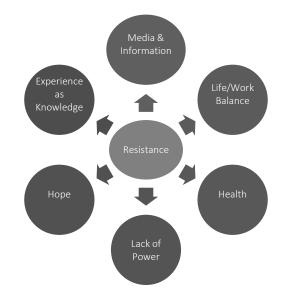


Figure 6: Theme, Category, Coding and Analysis: Category Identification

The ongoing analytic process also included discussions, presentations and written work on the preliminary findings and analyses. Each of the various activities undertaken furthered the analysis, contributing to the ongoing memoing, coding, diagramming, and theoretical development. These included radio, newspaper, television and web interviews, guest lectures and panel presentations, conference and poster presentations, workshops, publishing guest columns and commentaries in mainstream and academic media outlets, SSHRC Storytellers competition participation, discussions with my committee, local, national and international breast cancer research colleagues and key informants. Through all of this, returning to the transcripts, notes, memos, and diagrams clarified the connections and the theoretical insights, linking the understandings emerging with the research questions.

Individual interview summaries, ranging from three to six pages in length, were created based on each interview, post-interview notes, interview transcripts, research and interview questions, broad themes and categories identified to that point within and across interviews. Each summary contained a table reporting interviewee characteristics, demographic information, specific information derived from direct interview questions, individual components of the common data categories across interviews, paragraphs synthesizing the individual narrative and its context, and included notable quoted excerpts from the interview (see Appendix E). The creation of these summaries for each participant was an essential exercise in the analytic process, synthesizing what I heard, identified and understood in each of their narratives. The summaries were a critical addition to the comprehensive collection of documents related to the process and became another source of examination in the developing categories and codes (see Figure 7).

Figure 7: Theme, Category, Coding and Analysis: Category and Code Development

EMBLEMATIC EXCERPTS in CATEGORY and CODE DEVELOPMENT

٠	"we	were	bull	etproof"
---	-----	------	------	----------

- "I just knew"
- "how many flukes do you need?"
- "talking about it helps"
- "no wonder you got breast cancer"
- "women tend to put their needs last"
- "how I pictured hell"

- "that visceral sense"
- environmental health is a tack on"
- · "it feels very much out of our hands"
- "we do stand together"
- "a love/hate relationship with the Bridge"

Each of the text sources produced through the process (notes, memos, transcripts, summaries, maps) was analyzed to identify a "sense of both commonality and diversity across participants that may reveal possible analytical outcomes" (Charmaz, 2006; Solis, 2015, p. 1).

Kleinman's approach was adopted to exploring the narratives related to the research and interview questions. Together they guided the identification of the themes and concepts in the narratives. The insights generated from this stage evoked questions about the fit, or lack thereof, with the theoretical approach. Exploring the concepts drawn out in the narratives in response to the interview questions illuminated where Kleinman's approach alone was insufficient to explain the fundamental elements of the women's narratives. Drawing on standpoint theory, a socioecological framework (see Figure 8) assisted in the greater elucidation of relevant understandings of the narrative elements that would uncover the phenomenon being investigated.

Figure 8: Narrative Analysis Framework: Health is a Nested Set of Relationships

"Health is intertwined with and impacted by factors in the social world. Health is wholeness. It's a concept that cannot apply solely to an individual since people and other beings live within families, communities, ecosystems, and planetary-level conditions. The health of any part of the whole of this nested set of relationships is dependent on the interactions among them all. Socioecological models of health portray this multi-level complexity" (CHE, 2020).



Additional literature and theoretical reflections were incorporated into the analysis, including recognizing tensions, narratives of resistance, social inequalities, power, and conflict (Porroche-Escudero, 2011; Nielsen, 2019; Wilkinson, 2001; Porroche-Escudero, 2012; Popay et al., 1998; Emirbayer and Mische, 1998; Frank 1995; Ropeik, 2019; Porroche-Escudero, 2016; Foucault, 1973). These conceptual pieces—and the significant ways in which they tied into the idea of tensions—were integrated into subsequent stages of category and code development (see Figure 9).



#### Figure 9: Theme, Category, Coding and Analysis: Tensions

The process of analysis made it apparent that the broad themes, categories, and codes were interrelated. This is consistent with the interconnectedness of the information sectors as part of the cultural system illustrated in Kleinman's approach, as is emblematic of the experience of living as women located in a specific context and seen through feminist standpoint, and as represented in the nested levels of the socioecological framework. Recognizing the interconnectedness of the codes and categories led to distinguishing more analytic codes. The analytic codes drew on the texts and discourses employed by the women in their narratives. Reflecting on the analytic codes, I recognized the women's responses as more comprehensive than straightforward descriptions. Identifying the analytic nature of the concepts as presented by the women's narratives gave voice to their interpretations. Engaging with the codes through theory, the conceptualizations offered by the women became visible, and I was able to identify patterns and commonalities that uncovered the interrelationships between the overarching themes in the research and the narrative typologies that provided an analytic understanding of the phenomenon of understanding breast cancer risk and agency.

Kleinman's concepts of moral ordering and what matters most was used in conjunction with feminist standpoint nested in a socioecological framework as a means to analyzing women's subjective understandings of breast cancer risk knowledge and risk mitigation strategies. The synergies of these theoretical concepts contributed to further developing and generating codes and categories for analysis (see Figure 10).

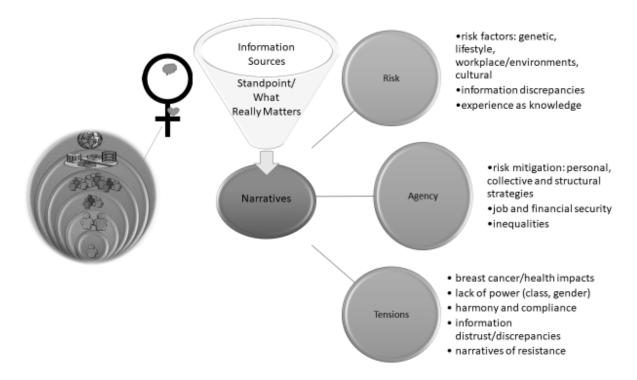


Figure 10: Mapping the Generation of Themes, Categories, Codes

The development of themes, categories and codes was executed manually on paper copies of the transcripts, notes, and memos. Later, the transcripts, post-interview memos and interview summaries were also uploaded to Dedoose, a qualitative data analysis programme (dedoose.com) and a coding process within the programme was carried out. Participant descriptors and characteristics were also entered into Dedoose for additional analysis levels made possible from the outputs of the data produced by Dedoose. The final theme, coding, category, and narrative typology developments all pieces of the analytic process—were cultivated through writing drafts of the findings and analysis chapters.

The women's responses to the interview questions provided identification and description for constructing the geographical, social, political, occupational, and environmental context for the experiences, knowledge and understandings of breast cancer that inform their narratives. The subsequent chapters address and analyze the narrative themes and typologies identified in the women's narratives. The comprehensive analytical framework that guided the analysis (including the diagrams and maps above) is embodied in the findings of the forthcoming chapters.

## Ethics

An ethics application for collecting information via interviews was prepared using the Tri-Council Guidelines for Research Involving Human Research Participants and submitted to the University of Windsor Research Ethics Board. Ethics clearance was obtained in February 2018. Specific ethical considerations for this study were minimal.

The study observed an ethics of care (Edwards & Mauthner, 2012, p. 4) that attends specificity and context rather than absolute norms. Guidelines for ethical action grounded in the specific context (Edwards & Mauthner, 2012, p. 19) of health and illness, specifically breast cancer amongst those who may have had a diagnosis themselves or are worried about a potential diagnosis considered. The potential for possible negative repercussions in the workplace by management or "the company," or even co-workers, and any concerns this caused the participants were given careful consideration.

During the research process and throughout the project, reflexivity and negotiating ethical dilemmas within the participants' contextual or situational standpoint were embraced, ever mindful of raising anxiety or fear amongst the women due to the required interactions (Carroll, 2010). Confidentiality was strictly maintained—I was the only party with access to all of the participants' contact and identifying information. Anonymity was protected through the use of pseudonyms and removal from interview transcripts and data of any information that could potentially identify any participant from materials accessible to anyone other than me.

#### **Assumptions and Personal Stance**

I was personally motivated to conduct this research given my prior experience in occupational and environmental health research and advocacy, particularly my involvement in studies of women and breast cancer, and advocacy work around research findings related to these issues. This evidence-based exploration of women's understanding of breast cancer risks, particularly whether and how they incorporate environmental risks in their narratives, is a continuation of my work to influence prevention policy and regulatory revisions. I see this research as an opportunity to provide insights and evidence of a special ontological status that can contribute in new ways to an understanding of the broader issue of environmental breast cancer in the context of improvements for women's public health. The question of what counts as knowledge is also at the forefront of my study design. Knowing that "evidence is never morally or ethically neutral" (Denzin, p. 647), the knowledge garnered from this study could catalyze agency and advocacy. This study aims to illustrate an aspect of the social and cultural world of a different ontological status than the status typically associated with breast cancer's cellular causes (Carroll, 2004, p. 2).

In approaching the complex phenomenon of women's understanding of breast cancer risks related to the environment, this study accounts for complexity and specificity while taking up a perspective that sees social science as emancipatory, but still capable of achieving validity, rigor, value, and resonance. "Humans are complex, and their lives are ever-changing. The more methods we use to study them, the better our chances will be to gain some understanding of how they construct their lives and the stories they tell us about them" (Fontana & Frey, 2005, p. 722). Through narrative interviewing and discourse analysis, we can address some of the human complexity of breast cancer knowledge not reflected in epidemiological studies.

## **CHAPTER FIVE**

## Narratives of Risk: Spaces Between Dichotomies

Mary's story was not unlike those of many of the women I interviewed. She was enthusiastic about the job's benefits, steady paycheque, expected pension upon retirement, and a sense of family among her co-workers. A Windsor-area resident with a University education, she enjoyed life with her husband and children and made the best of it. On the day we met, Mary was celebrating her birthday and dealing with the fear of recently finding a lump in her breast and waiting for test results<sup>6</sup>. The possibility of a breast cancer diagnosis was at the forefront of her consciousness during our conversation that day. Like most of the other women interviewed, Mary's narrative of understanding breast cancer risk began with genetics and family history. She was also descriptive about environmental risk factors and aspects of her working conditions and the Ambassador Bridge's surrounding area she felt were conferring risk upon her and her co-workers. Mary wanted answers about why there are seemingly so many breast cancer cases among her co-workers, including whether the environment around them might be among the causes. She said:

I mean, if you look at the correlation, if you look at the environmental factors [the number of cases] does make sense. It is alarming to me right now that it's such a high number... If this is something that is happening based on environmental factors, and I am in the middle of it, it needs to be known.

Mary's understanding of breast cancer risk stemming from the environment did not fit her formal understanding of risks as predominantly genetic or hereditary, which concerned

<sup>&</sup>lt;sup>6</sup> I was advised later by Mary that she did not test positive for breast cancer.

her. Her narrative brought out descriptions of her experiences of risk in the workplace environment, contrasted with the unavailability or gaps in information on these risks. These experiences lead her to advocate for improved knowledge translation and working conditions for herself, her co-workers, and the future workforce of women at the Bridge.

This chapter focuses on answering two of the study's three research questions: 1) How do women who work (or have worked) in an environment identified as posing an increased risk of breast cancer construct narratives and understandings of the risks? 2) How do women place the environment in their narratives? Using the analytic framework comprised of Kleinman's cultural approach (1978), feminist standpoint theory (Smith, 1997) and socioecological theory (Bronfenbrenner, 1977; Schettler, 2015; CHE, 2020), this chapter discusses and analyzes the role of information and the incorporation of various discourses of risk, including spaces between the dichotomies of risk, in the construction of women's breast cancer risk narratives. Additionally, the chapter explores the narratives for how women's standpoint—including "what really matters" to them and the complexities of their experiences as apprehended in their socioecological nestedness shape their risk understandings as presented in their narratives.

### **Understandings of Risks**

Risk is about exposure, danger, probability, or expectation of exposure and therefore encompasses uncertainty. Intrinsically, risk understandings and mitigation strategies are complex and multifaceted and necessarily rooted in their experienced context. Despite the inherent complexity, risk understandings are often framed as a dichotomy of either being *at risk* or *not at risk*. Breast cancer risk discourses are also often presented as dichotomies, where being at risk is characterized by genetic and lifestyle factors, and being 'not at risk' is ascribed to social conditions, inclusive of environmentally produced risk factors for breast cancer which tend to be overlooked, misunderstood, ignored, and even omitted. Between these dichotomies are real-life conditions. The spaces between are emblematic of gaps created by professional and mainstream information sources by omitting structural risk factors such as occupational and general environment-related exposures. The gaps in mainstream information sources and messaging about these factors create the impression that they do not pose risks. However, scientific studies illustrate otherwise, as discussed in the opening chapter of this dissertation.

Women's experience also suggests that these environments produce risks for breast cancer. Different information sources create varying degrees of acceptance and rejection of varying risk factors. The phenomena of these variabilities in risk assessments are evident in women's understandings of environmental breast cancer risks. Of importance to the analysis of risk narratives herein is the recognition that the neoliberal sociocultural context that the women in this study live in (and as contextualized in earlier chapters) is a critical influence on health and risk narratives and contributes to the dichotomous characterization of breast cancer risks that women's experiences so eloquently expose.

When women talk about breast cancer risks, uncertainty becomes evident as they describe what they know and suspect—their fears, and how they manage those worries. Risks, Samantha observes, create discomfort. She describes what she felt before coming in to be interviewed: "I came in here and I knew it was going to be in some ways difficult to talk about because of how painful breast cancer is because I have been near it. How

painful it is to even think about the risks," she says. As described herein, breast cancer risk narratives are multifaceted, complex, reflections of personal, sociocultural influences including gendered and class experiences, and are a window into the interconnectedness of social relationships. Women's reflexivity is reproduced in their breast cancer narratives as spaces where they intervene using their experience and negotiate among multiple and often dichotomous discourses.

### Genetics and Heredity

Genetics and heredity are the predominant risk factors women speak about when they first name breast cancer risks in their narratives. That the women initially name these risk factors fits with dominant breast cancer risk discourses and corresponds with the neoliberal, individually focused model of risk embraced by the medical establishment and mainstream messaging. This section will illustrate how women's narratives do not fit neatly into the simplistic binary found in the dichotomous discourses of genetics/heredity vs. environment. These dichotomous categories also imply binaries of controllable or not controllable. Neither of these binaries captures the complexities of women's lives and experiences. Nor do they demonstrate how evidence of environmental risk factors for breast cancer reflects women's lived realities within systems embedded in a socioecological framework. Women's understandings of risks tend to mediate the poles, the nuances of the risk experience found in between, emerging over the course of their narratives. Though genetics and heredity were often combined later in discussions of the workplace environment, women weighed these risk factors together in constructing their narratives.

Erin, a woman in her twenties, who in earlier years as a University of Windsor student worked at the Ambassador Bridge Duty-Free Shop, told me what she thinks of when she hears the words "breast cancer." Her response was indicative of many of the narratives.

I think lumps in boobs. I think about getting breasts removed because they found certain genes that are linked to breast cancer. That's kind of my knowledge of it. If you have it, you probably have to get breast tissue removed, and it's a genetic thing typically.

Erin's foregrounding of the genetic connection to breast cancer, which evidence has established is of minimal importance compared to other factors, is not surprising, given this is a prevalent discourse and an emphasized risk factor in much of the professional and popular information sources.

Kathy, a woman in her 40s, worked for CBSA for close to 20 years. She now works elsewhere, but like Erin, shared the belief that genetic predisposition is the most significant risk factor:

I haven't really had a whole lot of experience with breast cancer. I personally just thought it was more of a genetic thing, like a hereditary thing that increased your risk way more. I would say that would be your highest risk. I mean, I know it can affect anybody, even men, but to me, it was more if it ran in the family and that sort of thing, was your highest risk.

Kathy qualified that she did not have a lot of "experience" with breast cancer and was uncertain about breast cancer risks, but her understandings reflected the traditional breast cancer risk discourses. Though Kathy and Erin began with genetics and heredity and were afraid, they both later point to the workplace and environmental conditions as sources of risk and correspondingly see a role for themselves and society collectively in addressing the exposures women face.

Erica, in her 30s, and a CBSA employee for more than 15 years, also focused on genetics but discerns more than genetics and incorporated the environment as a risk factor:

I personally think it's more in your genes, more hereditary. I don't think there is much else. I think there is some environmental, but I perceive it more as a hereditary thing. I don't have any concern really with it, but I don't have it in my family, so I haven't been directly affected by it. So a part of me is, well, no one in my family has it generation after generation, so I guess we are lucky in that aspect, and I haven't had to—I don't want to say had to—but I have never worried about that knowledge because we haven't dealt with it personally.

Like many of the women, Erica's narrative of risk demonstrated knowledge of a multiplicity of risk factors. Her description was reflexive, and knowledge and understandings of risk in her narrative incorporated a combination of information sources and personal interpretations.

The narrative provided by Shannon, a woman in her 30s, illustrates how personal experience contributes to different considerations of risk factors such as genetics and environment over time. These experiences lead the women to more complex interpretations of risk. Shannon's story combines experience with other sources of information in the construction of her risk narrative. She shared her thoughts about a friend's breast cancer, dealing with seemingly contradictory information that challenged

her thinking on the issue. "I think I made the connection at that time. So, I am like 'how is this woman who is super healthy, she did not drink, she was eating a health-conscious diet, and drinking lots of water and taking care of herself, exercising, how does she get breast cancer?" Shannon's standpoint led her to look to the environment and to the creation of a dichotomy.

For me, it was one of two things. It was either genetics or her environment. And I think from that time when she passed away, and I worked at customs still at that time, I started kind of thinking to myself, if my environment is having an effect

on my health directly, and if I know it is, how am I going to continue working? Shannon was surprised when I told her that science says five to ten percent of breast cancer cases are genetic. Despite her concern about the environment, her perception was that genetic risk was most significant. "Really? I would say that I had no idea. I would think it would be the opposite. I would think like eighty percent or something would be genetic." Shannon later described her confusion. "When my doctor talked to me about [breast cancer] originally, he said that I had the lower chances of genetically having breast cancer because my mom has not had it, which I thought was confusing because my grandma still had it, and my aunt." Shannon ultimately left her job with CBSA because of concerns about the risk posed by her workplace environment. The example provided by Shannon illustrates how women incorporate subjective understandings and the interplay of risk factors—personal experiences, family history, genetics, and the workplace context—to inform understandings and choices and underscore discrepancies around breast cancer risk understandings and risk mitigation.

The narratives of the women workers are reflexive, with knowledge and understandings of risk constructed from various information sources and personal interpretations situated in a societal context of neoliberal values, policies, and practices. Confusion and a lack of clarity regarding the possibilities of risk emerged at times. Fatima was retired after more than 30 years as a CBSA employee. When asked about her understanding of the causes of breast cancer and her knowledge of breast cancer cases and compensation among her co-workers, Fatima mentioned several factors and showed she had some doubts. "It could be anything. Work, for sure. Part of it might be family, may or may not be. They say supposedly that if you are on shift work on midnights, there is more of a chance of breast cancer." She talked about the media messaging around breast cancer, with the focus on genetics and family history, declaring, "I think they try to put out a good message, but it doesn't necessarily work. You know, go get tested, go get your mammograms. I mean, you can get breast cancer younger than thirty or forty, when you are into your twenties and men can get it too." Her answer illustrated the complexity of sorting out the multiplicity of risk messages in constructing understandings of breast cancer risks.

Kimberly, a woman in her 40s and going on two decades as an employee of CBSA, explained her knowledge of breast cancer, disclosing "truthfully, I am not too familiar with it. I honestly think the only thing I would be able to say that I feel would be knowledgeable about it is that I know cancer itself is genetically linked to some degree. You are more susceptible genetically. That's about it. That's all I am really aware of." Kimberly expanded on her answer, moving to her personal experience in constructing her risk narrative: I don't know anyone in my family that has had cysts in their breasts or anywhere really in their body. I have had [cysts], and it has been since I have started working there [at the Bridge] that I have noticed it. Obviously, that has been the majority of my career, so one could argue that, well, that's where you spent your formative years. But knowing my family history, I haven't heard of anybody who has had those issues as of yet. So that makes me wonder if the environment that I am working in on a daily regular basis is contributing to my personal health issues.

Kimberly's narrative drew on the professional information, highlighted family history as important, and incorporated her experience working at the Bridge. Her standpoint, noticing tensions and contradictions, leads her to question whether her workplace environment contributed to her breast health and, in doing so, challenge the dominant explanations. The way Kimberly talks about risk factors creating an overlap in biomedical discourses and sociocultural understandings of risk while trying to reconcile their roles illustrates the interplay of information sources and their relationship.

External information and knowledge systems play a role in shaping women's evaluation of risk factors as mainly genetic. When women challenge genetic risk as explanatory, it is through a reflexive process. The women use their standpoint, their experience, to counter external knowledge and measure externally produced sources of information against their experience. In this process, the women do not wholly shift to environmental risks, which would create a false dichotomy between genetics and the environment. Instead, the women construct more reflexive and self-conscious understandings of breast cancer risks as multi-factorial, operationalizing experiential knowledge and observations while negotiating the complexity of factors to producing their understandings. The deliberations and evaluations by the women I interviewed become evident as their standpoints emerge in their narratives.

# Lifestyle and Life Course

Lifestyle risks for breast cancer figure prominently in breast cancer awareness campaigns. Perhaps this explains why the lifestyle discourse came up in the narratives almost as frequently as genetics and the environment. In her 50s and a CBSA employee for more than a decade, Mary Anne provided a detailed description of how she sees lifestyle factors, particularly food, and chemicals as implicated in breast cancer risk. "My opinion is I think it's the food. I really do. I don't think it's hereditary in that case. I tend to think it's the crap we eat." She moved to a prescription for avoiding risks, advising, "Stay away from all the junk and all the preservatives," she said, "and eat healthier, fresh." Mary Anne did, however, recognize risk as more complicated than just food and incorporate personal reflections from her standpoint:

I think stress is huge; food is huge; pollution is huge; not an active lifestyle is huge. I think it's all those pieces of the puzzle. Because did we hear about cancer 20 years ago? Yes. But did we hear about it as much as we do now? No. So I think it's just more chemicals now. I mean, they used to do pesticide spraying on the lawns, but now they are not allowed to do that, and they used to be able to have Round-Up, and you can't have that now. And so, they—they as in

organizations—find out later that that stuff is not too good, we'd better ban that. She bemoaned the slow pace of alerting the public to dangers, noting, "it's unfortunate that it takes sometimes a couple of years to find out that those aren't safe products to use." Mary Anne's narrative of breast cancer risk exemplifies her standpoint and how her understanding of risk is social and cultural. The multilevel and interrelated influences of her socioecological context are evident in her narrative, including how knowledge shifts over time regarding institutional information, changes in legislation, and chemical substances regulation.

Larissa, a woman in her 30s who had no awareness of breast cancer cases at the Bridge, nor the compensation case, illustrates how the lifestyle discourse permeates women's risk narratives, combined with heredity, genetics, and life course risk factors.

It would be external factors, like if you smoke, things you eat or drink. So, I would probably say from what I read and what I see, your heredity. You can't change your genetics, so if it runs in your family, that's a big one. And age, because you probably have more chances as you get older. And pollution. I would say those are probably the biggest ones that I know of.

Though she mentioned several factors, Larissa first emphasizes lifestyle factors, then genetics, age, and pollution across the life course.

Julie also placed age as an important risk factor in her narrative, though she challenged the prevailing notion of the association between age and breast cancer. She is a woman in her 40s, a CBSA employee with more than ten years of experience on the job, and an awareness of multiple breast cancer cases among her co-workers. Combining information from multiple sectors with her own experience and standpoint as a woman to construct her narrative, she said: "You hit forty and [breast cancer] is something that all of a sudden becomes an issue with women. I know you can get breast cancer in your 20s. I have read enough women's magazines, where it doesn't seem to be age defined. But it seems to be, as far as medical practitioners, and they just seem to focus on it more once you hit that mark [40 years of age] for some reason." From Julie's standpoint, there is a seeming inconsistency in information about age and breast cancer risk – she is questioning why the focus on breast cancer at age 40 when younger cases and cases in men are indicated but without causal explanations.

Jackie, a former CBSA employee in her 30s, was diagnosed with breast cancer and raised caution about age messaging as a risk factor. "I think they need to know that it's not your grandmother's disease or your mom's disease anymore. This is affecting women, not so much teenagers that I have seen, but there have been cases, women in their early twenties." She told me about her thoughts at the time of her diagnosis of breast cancer, saying:

I found the lump, and because of my family history, I kind of presumed that that was what the conclusion was going to be. I kind of already knew, and I think it was just all very sudden for me because I think I had anticipated it... in the back of my mind, I had always presumed that because the gene does run in our family, that eventually I was going to be diagnosed. I guess I just didn't think it would be as young as I was.

Jackie's personal experience, family history, knowledge of evolving breast cancer trends, and current involvement in cancer care education through a provincial organization came together in her narrative with a message that runs counter to the traditional idea that breast cancer is a disease of older women. She explained and filled in the gaps in the complexity of breast cancer development, filling in the spaces with the complexities inherent to the casual web of factors science implicates in breast cancer causation, particularly for young women. "I think it is really important to understand the linkages between the genealogical factors and the environmental factors."

Jackie's perspective was evident in her narrative as she detailed her family history of breast cancer and her belief that there was an interplay of breast cancer risk factors that women need to understand. Her narrative illustrates how her standpoint, like those of the other interviewees, evolves and shifts through her negotiations of the complexities of her experience in combination with other knowledge sources. Jackie also demonstrated awareness of environmental contributors beyond the Bridge's experience using knowledge from her broader social context to situate the environment as a risk factor in her understandings. "On my street alone, my mom and I were diagnosed, and then a woman across the street, one of the neighbours, was also diagnosed. My aunt didn't live very far from us when she was diagnosed." She then questioned the role of workplace exposure. "I am just wondering if any of that [environment] contributed to my diagnosis as well as working in those [risk bearing] environments." As with so many others, Jackie's narrative names distinct spaces but contemplates their interrelatedness in contributing to risk for breast cancer. Here, Jackie's standpoint illustrates how the intersections of the socioecological context manifest in the realities of the spaces that comprise those between dichotomous portrayals of risk as either individually borne (genetic/hereditary/lifestyle/voluntary) or environmental (external exposures at home/work/play/involuntary).

In her 60s and retired from CBSA with over 30 years as a customs officer, Sophia Belle was diagnosed with breast cancer while still working. Her story illustrated how she grappled with the portrayal of age as a risk factor in isolation from other risks in

123

combination. "When you're in your twenties, and you haven't had any serious health issues, you think you're bulletproof. So, when I was, I would say, well into my 30s, I never really considered [the Bridge] an unhealthy place to be." Though Sophia Belle recognized age as a risk factor, her standpoint shaped her analysis, which shifted and changed over time, as she grappled with tensions and contradictions in her experience and the different discourses of risk, arriving at the belief that as a Bridge worker

at a young age, the work environment could also be a breast cancer risk factor. Sophia recalled a conversation with her oncology doctor, saying he "suggested at the cancer centre that a very strong possibility was [workplace] environmental factors." Her doctor's recognition of environmental factors is notable as many women reported their doctors rarely if ever, related breast cancer risk with workplace exposures. Sophia Belle now attributes her breast cancer diagnosis to her early exposures at the Bridge. Her narrative reveals that her standpoint on breast cancer risk shifted over the life course as she incorporated various information sources and sociocultural influences into her risk understandings.

Annie, who worked at the Bridge for nearly a decade, was educated on health and environmental issues. She garnered her knowledge from many sources and was also influenced by her own experience. Annie's narrative incorporated the dominant lifestyle breast cancer risk discourses as she described her surprise at having been diagnosed with the disease. "I breastfed my children, I have never smoked, I barely drink, and by that I mean I would have wine at dinner at my in-law's house, we don't have wine at home for dinner. So, I thought that those were risk factors. I thought I ate fairly healthy. I was kind of into the vegetables. I wasn't overweight." Annie says that originally, she did not consider the environment as a risk factor, but it now influences her risk understandings. Her narrative explicates how events and experiences over the life course shape how knowledge of risks changes through different contexts and one's standpoint. "When I was diagnosed, of course, I thought about all of the reasons maybe I got breast cancer. But working at the Bridge didn't really even come into it. I just didn't even think about that. Now I wonder." She then explains how her work environments as possible risk factors became incorporated into her cancer narrative:

I was just shocked that I got breast cancer. I didn't think of working at the Bridge as a risk, and I didn't think of having worked in Chemical Valley [in Sarnia, Ontario] as a risk. And it still never really dawned on me, I think, because it was so far in the past that I had worked at those places until we were driving to Sarnia one time and my son said to me: "No wonder you got breast cancer. You worked in two of the most polluted places in the province."

Annie's standpoint, as reflected in her narrative, shows how dominant breast cancer discourses influenced her. Her personal experience and recognition of her social context helped Annie make connections and recognize contradictions that challenged the closure of prevailing discourses. This opened up the possibility of interrelated and combined risk factors in her lived and worked environments.

Annie's, Sophia Belle's, Jackie's, and the other women's understandings of breast cancer risk are a negotiation of understanding of their own lives and changes over the life course. As described from their standpoint, the women's breast cancer risk narratives as they discuss lifestyle risks, illustrate the interactions of exposures and the life course perspective of health in the ecological model. Though there seems a consistency across narratives that women understand health in different ways over time, they nonetheless struggle to reconcile their personal experiences and interpretations with biomedical knowledge of risk factors, their standpoints evolving in the spaces between seemingly opposing accounts. The dichotomous portrayals of breast cancer risk are recognized by the women and figure into the experiences they draw on in the construction of their risk narratives that mediate these poles. The women challenge the experience and understanding of breast cancer risk dichotomies as they recognize how and where their experiences and observations do not fit the dichotomies. Instead, women's risk narratives are constructed from knowledge in spaces of risk between dichotomies throughout the socioecological frameworks where their lives are lived

## Incorporating Conditions of the Work Environment

Mary, a woman in her 40s who worked for more than a decade with CBSA, told me, "I hate to think that there is a higher correlation between working at the Bridge and breast cancer, but I do know a few of the ladies there have had breast cancer, so is there a correlation?" Though Mary seemed to consider her working conditions as a possible risk factor for breast cancer, she was uncertain. For many women, information from professional and popular sources is considered along with their experiential knowledge, including their observations and awareness of breast cancer cases among their coworkers. These pieces of information lead them to consider the possibility of environmental risks for breast cancer. Lack of access to information that might confirm their suspicions is viewed as an obstacle and contributed to continued uncertainty about breast cancer risks. Though the women drew connections between workplace exposures and breast cancer from their standpoints, their interactions with others, and the dominant discourses operating about risk undermined their confidence in their observations. Still, the women asserted what they knew about their work environments in their narratives, reporting how they shared this knowledge set with one another. By sharing their everyday experiences about themselves and their work environments, women's knowledge—a form of folk knowledge—is made real and legitimized as they comprehend their environmental risks for breast cancer. The relationship between their experience and other women's experiences is part of the process of shaping risk interpretations, knowledge construction, and women's standpoint.

Multiple social and cultural forces are reflected in constructing women's breast cancer risk narratives, including from within the workplace. Sophia Belle recalls: "We started getting things [from the health and safety committee] about hazmat, hazardous materials. But it was in its beginnings... And I think we still all have this mindset that it was only bad if you could see it or smell it. And that is probably one of the biggest tragedies for everyone." For Sophia Belle, seeing it with her eyes was not necessary. Her own experience told her that there are risks associated with exposures that are not necessarily readily detectable by sight or smell. Her combined personal experience and scientific knowledge of workplace exposures influenced her narrative.

I truly believe that the work environment was definitely a partial cause [of my breast cancer]. You've got shift work, which is really coming out now [as a recognized breast cancer risk factor]. And then all of the benzene and diesel and all the additives that are in gasoline. And we're breathing this stuff in. You don't even think of that. And there was this concept that if you're inside a building, the building protects you from the carcinogens. Well, that's not true because quite a

few of the women who've been diagnosed since me were not officers, they were clerks, [they] never went outside.

Sophia Belle's standpoint helped her see the interconnectedness of the body with the workplace environment and the cultural and institutional knowledge about breast cancer. The multiplicity of experiences and the interrelatedness of social environments were reflected in her narrative in a way that created questions about dominant breast cancer risk discourses.

Sara's tenure with CBSA almost mirrors Sophia Belle's. She describes changes in workplace conditions that she relates to harmful environmental exposures at the Bridge. "You have to think in the 60s and 70s, the traffic wasn't that bad," she explained. "It wasn't that heavy. I would say it was more from the late 80s, and on that, it got really bad, that it was so busy." Sara worked on occupational health issues over the years. She was unwavering about traffic as a breast cancer risk factor. "It's that diesel particulate matter and the sheer volume of trucks. Let's face it."

Traffic was almost universally named and implicated in the women's narratives as an environmental breast cancer risk, as revealed in the following excerpt from Susan's interview. Susan was convinced the Bridge environment was unhealthy:

I blame work for a lot of things because, for twenty years, I worked around diesel fumes and exhaust from cars. It's always there, so for me, I think it is the biggest risk. It's not whether or not I go to the back of a trailer and am exposed to a chemical. I don't ever think of it that way, but I do think that I sit in that booth and breathe in those exhaust fumes every single day...I think we are all very much aware of the noise and the air pollution that we are exposed to every day." Lindsay, who talks about her strong female role models who influence her thinking about health and breast cancer, described the traffic conditions at the Bridge and how they made her feel.

Honestly, it's unlike any place I had ever worked. Of course, traffic is always coming through. And you have to go outside for a lot of tasks. Even just the way that physically it's set up. You walk through the truck parking bay to get to and from your parking lot, so you are walking through that. And I can tell you it never smelled good walking through that. You could even feel the grime. Coming out of work any given day, you feel like, I just want to shower...like you could definitely smell the fumes the trucks and the cars put out.

She told another story that reflected the impact of the traffic conditions at the Bridge.

One of the jokes between the employees was, everyone has their *Duty Free pants* and their *Duty Free shoes*... you are given a uniform shirt to wear, but your *Duty Free pants* and your *Duty Free shoes* you can't wear anywhere else. That is exclusive to Duty Free, and it is gross, and you can't wear those things anywhere else. So, my shoes, I threw out after my last day, literally on my way home.

Lindsay said she "absolutely" sees a connection between these conditions and breast cancer risk.

Dana, who has over a decade working at the Bridge, was a positive, optimistic person. She saw risk mitigation as the responsibility of individuals, workplaces, and the medical system. Dana's description of her exposures at the Bridge illustrates how she sees her health as nested in her own body, workplace, and the broader environment. When you see a semi [truck] sitting there idling, because they are waiting for however long for the vehicle in front of them [to pass through customs], and that is just one truck. You can smell and see what is coming out of the vehicle. That cannot be good for the environment at all, not with one truck, but of all the trucks, and not just at this border crossing, every border crossing. That's a lot. And think of how that affects your environment, and that's *your* environment.

Dana went on to say, "When you think [about] what you are actually breathing in. And how does that affect your health? A lot of our toll collectors that worked down in the compound years ago have cancer of some sort as they got older." From Dana's standpoint, breast cancer risk factors are not limited to biomedical explanations, and the evidence of this for her was derived from experiencing workplace exposures.

It was apparent that Janis' consciousness about environmental risks was well developed at the time of our conversation. Retired after more than 30 years with CBSA, and with a breast cancer diagnosis behind her, Janis mentioned several environmental exposures that concerned her. She describes conditions going back to earlier years in her job with Canada Customs and finishes by saying, "We all just all thought, God, I hope we don't die here." Cindy, a CBSA employee nearing three decades, felt the health and safety training she received was insufficient. The volume of trucks at the Bridge was at first a surprise, but over time, their presence turned from surprise to concern.

I do remember when I first got hired, going out there, and they gave us a tour, and I saw all those trucks and I was completely overwhelmed. I remember telling everybody I could think of, 'You wouldn't believe how many trucks cross that bridge.' And then when I started working, I think that it started to slowly sort of dawn on me, seeing how dirty everything got in that environment. [That's] what I was breathing in every day.

Samantha's description was evocative: "In my mind, that scene looked like how I would picture hell. That's what I always thought of every time I crossed the Bridge, 'This looks like hell.' And it was a horrible smell, and that was my impression of the whole region... So, no, it's not a healthy place to work. Just on that alone." After a decade with CBSA, Samantha sees work as a necessity to provide for her family. She fears for her own breast cancer risk, especially given her family history of breast cancer and knowledge of the environmental factors she is exposed to.

Like Samantha, Shannon spoke about family history and loss to breast cancer as she described the working conditions at the Bridge. She talked about management's workplace culture, where monetary considerations seem to outweigh concerns about the occupational exposures. She contrasted the Bridge with other border ports: "We went to Vancouver [port], and actually nobody idles there. Any bus or car gets shut off. So, I wonder if the rule there is 'no idling'? And the difference in their air quality versus ours!" She considered this a viable solution that could be adopted at the Bridge to reduce vehicle exhaust and the associated breast risk. Although Shannon no longer works for CBSA, ultimately leaving out of concern for her health, she worries for the women working there—not only because of the physical environmental exposures, but also the negative culture that reinforces a set of values that see money as more important than women's health.

Lorraine, with 25 years at the Bridge, talked about workplace culture and low morale. From her standpoint, there is a connection between negative culture and breast cancer risks. Lorraine also linked morale to the uncertainty around the relatedness of the number of breast cancer cases to workplace exposures.

You see it every day with all the trucks and all the fumes. And then you have people who have concerns with it, and you hear about [breast cancer]. And then all of a sudden, it's just one person and then another person and then another person, and you think, there has to be a connection here. We all work at the same place, and this is where I am spending most of my time now. Something must be going on.

She described multiple aspects of the working conditions that caused her concern, including the toxic work environment—everything from the buildings to the air quality. Lorraine also cited shift work, ergonomic issues, and other stressors, suggesting they all take a toll on the women's health. She also discussed the challenges of dealing with and getting any formal recognition from CBSA management and the Workplace Safety and Insurance Board (WSIB) of workplace illness, including breast cancer.

Maggie was one of the last women I interviewed for the study. She spoke at length about her family and the influence her father, a scientist, had on her perspectives of health and environmental contributors to illness and disease. A world traveller with a post-graduate education, Maggie had incorporated her diverse information sources and life experience into her narrative. She relayed her belief that her breast cancer diagnosis might be related to various exposures over her life. She worked at the Bridge for fewer than five years, but when I told her about the number of cases of breast cancer I had heard reported in the course of interviewing, she said, "I am not surprised...I don't think I would have been surprised even if I wasn't diagnosed with breast cancer. There were a lot of trucks that never shut down their engines." Maggie's standpoint provided her with a perspective that saw the relationships between breast cancer risk and workplace conditions. Erin, who said her brief experience in the Bridge environment concerned her, referred to many of the same exposures as Maggie and concluded: "obviously your environment is going to affect your body; your breasts are part of your body." Erin, Maggie and the other women constructed narratives of breast cancer risk that inevitably drew on their experiences and observations while working at the Bridge, reveal how sociocultural experiences are weaved into health narratives.

Bonnie started with Customs when female border guards were "searching trucks in pumps." "When I worked at the Bridge, and when I worked for Customs, there were people around me who had breast cancer. I would say, 'What's all the cancer? Everybody is getting cancer!' Retired after over 30 years on the job, Bonnie said her breast cancer was a "nightmare." Lily also spoke of the many women at the Bridge who had breast cancer.

It's been on our minds every time we hear somebody: 'Oh, I have breast cancer,' we think; 'Geez, you know, they worked here.' Whether they were officers or administrative or clerical, it still hits you. You kind of have to wonder: 'What is it about my environment?' I worked shift work, and I worked those truck lines a lot, the diesel and everything...we were supposed to have fans, exhaust fans up on

top. Not in the booth but right above where the trucks are. They never worked. Nonetheless, Lily loves her job, the benefits, and the opportunities. Her breast cancer diagnosis and awareness of many breast cancer diagnoses among the CBSA workforce brought her to challenge heredity's dominant discourse. "[Breast cancer] doesn't run in my family, and I work with so many people that have had breast cancer, and we all worked in the same environment," she said. For Lily, the workplace environment could not be disregarded as a risk factor for breast cancer.

Aside from the truck fumes, other commonly cited work-related risk factors, included shift work, radiation, and stress. The number of occupational risk factors mentioned and how the women placed their understandings of workplace risks for breast cancer among the dominant breast cancer risk discourses suggest a negotiation of factors, assessed through their subjective experience and contexts. Women's folk knowledge the knowledge, jokes, and stories they share—is part of their interpretation of risk and the shifts in risk assessment that contribute to women challenging medical and neoliberal knowledge in their narratives or breast cancer risk. The knowledge circulating among women about their experiences, workplaces, environments, and conditions of risk gives them an impetus to think beyond medical and domain knowledge sources about breast cancer risk. The incorporation of various sources of knowledge, including theirs and other women's, leads to constructing their health narratives. Internal and external factors influence the perspectives women adopt about breast cancer risk from their standpoint.

## Sociocultural Systems of Risk: Disparities Between Discourses

The women's narratives, bringing many risk factors together, including the environment at the bridge, point both to the complexity and difficulty of assembling information from numerous sources in the construction of understandings of risk factors for breast cancer. The women identified interrelated levels of the socioecological system and the information derived from the different sources and brought out when the knowledge from these various sources seemed incommensurable. Disparities and contradictions among discourses give rise to women's questions and doubts about the dominant discourses when compared and considered with their own experiences that do not fit the prevalent messages often presented in dichotomies and binaries that suggest closure on breast cancer risk explanations. Women's experiences in their sociocultural contexts provide experiential knowledge of the spaces where risk is produced and not captured in the dichotomies, which portray risk as individually borne as opposed to ecologically produced.

With a 12-year tenure with CBSA, Mary confessed that based on her interactions with doctors, she thought the numbers for genetics would be much higher. "Because that is one of the first questions they ask you: 'Is there cancer in your family, does cancer run in your family.' So, for only five to ten percent, I am surprised." Maggie also described confusion sorting out breast cancer risk factor understandings, especially when faced with her diagnosis.

Somebody very wise once said to me: 'you know cancer is not your fault.' But I am trying to think of different factors it could have been —biological, or it could have been genetic, and it could have been environmental factors. And that is the frustrating thing because we don't know.

Maggie's standpoint incorporated multiple socioecological influences and challenged prevailing biomedical explanations. "They asked me about family history. That was all the questions, family history." Her experience with doctors focusing on the dominant discourses was much like other women in the study. Annie worked for nearly a decade at the bridge with experience in traffic, the warehouse, and an inspector. She spoke about the experience of talking with doctors at the time of her breast cancer diagnosis and during treatments.

They did ask me at each initial stage and then actually afterwards, too, if I had taken the pill, how old I was when I first got my period, if I still got them. So, they asked about that kind of thing, estrogen. And they asked if I had ever smoked and how much I drank, if I drank. I do not think they asked me anything about the workplace. I am quite certain I would remember if they had.

The dominant epidemiological paradigm and the discourses operating in the medical system reinforce lifestyle factors while creating a gap recognized by women who resist these explanations based on their experiences and standpoint.

Bonnie also questioned the biomedical perspective that omits workplace risk factors for breast cancer. "Why didn't my doctor bring [my job] up? She knew what I was doing for the last thirty-five years. Why was that never brought up? I don't even know if they asked me where I worked or what I did for a living. Especially at the cancer clinic, why aren't they taking that as part of your file?" She went on to say, "so many people were getting cancer. At one point, there was, I think, eight or ten of us in treatment and some you didn't know about because people don't tell everybody that they had cancer." Bonnie's questions illustrate how information from social, cultural, biomedical, and experiential knowledge can create confusion, discrepancies and even a sense of distrust. The information disparities also contribute to narratives that resist the dominant discourses about breast cancer risk. Annie was angry about the lifestyle and behaviour messaging in the media, and especially the message it sends about individual responsibility: I do get a little angry when I read stories over and over, and they are quoting local doctors and health agencies saying our area has higher than average cancer rates, and it is because we have higher smoking rates and higher obesity rates. I don't like that it sounds like you are just blaming the victim...The environment, I have no control over that, other than quitting at the Bridge. But the air that we breathe, I don't feel like I have any control over that at all.

From Annie's standpoint, the individualized discourse and focus on behavioural choices fails to recognize how women's breast cancer risk is nested in relationships and contexts where control is misallocated. Discrepancies between what women are told about breast cancer risk and what they experience and observe are frequent aspects of the narratives. Trying to resolve these discrepancies is also prevalent. The manifestation of these discrepancies is illustrated in the narratives when their standpoint, located in their socioecological framework and inclusive of discourses, uncovers the interplay between internal and external social factors in breast cancer risk.

A CBSA worker of nearly 20 years, Kimberly drew on conversations about breast cancer with co-workers as a critical information source. "This topic has not been a quiet or dead topic at work. It has come up. It has been passionate. I have been there a little bit longer than some other people, so maybe it's also just because I've heard the stories. Officers that have had breast cancer have had to be off, have had surgery, went through chemo." Julie, a long-time CBSA worker, also drew on co-worker conversations as she challenged dominant messages: "Yes [we talk about breast cancer]. Absolutely. Because it is not normal. As much as they [the employer] get the air tested, they say, 'Oh, it's fine, it's fine,' I don't think that concentration of fumes, I don't think it's normal. I don't think it's normal to be exposed to that amount for the average human."

Julie's risk narrative also brought out the problem of trust. "I think you really have to kind of syphon through all that, you know, what has relevance and what doesn't. I guess you just also have to find not only what is kind of real and not real but also what works for you." Many of the women's narratives raise trust and information disparities, and internet-based content and the discourses that circulate on some websites contribute to these problems.

Erica, a long time CBSA employee with an educational background in human health, describes how she pieces together knowledge from various sources:

Every once in a while, I will think about [studies on cancer risks], like when I see the amount of trucks passing through or even when I am working in the booth, and it kind of reminds me. But it's a quick in-and-out thought. [I want] more knowledge because one girlfriend gave a few stats, and when she mentioned it, I [thought] I really don't have any real knowledge. I know it is out there, I know it happens. You see breast cancer awareness everywhere, but it's pink. You see, pink, that's what you see. You don't see stats. You don't see information on what we can do to prevent. We don't have information in our faces on what you can do to help.

Larissa, one of many CBSA workers with a criminology background, also spoke to a lack of confidence in the commonly available information. "I try to check the sources I have, but even when you have reputable sources, you still don't know the background of who is paying for these reputable sources." Evident in these accounts are the interrelationship complications and sometimes conflict between multiple sectors in constructing the experience and understandings of risk. This phenomenon of influences on understanding of risk as brought out in the women's narratives reflects power disparities in the nested set of relationships that humans and their health exist in.

Disparities in information and how this relates to trust and power were central concepts in Erica's narrative. "[The work environment] it's really bad, and it is brought up to our health and safety [committee]. And they bring it up to the Bridge Company, but they will say it is something else. They will say the air is fine. They will say there are no issues." She went on to say:

It's sad. I think it's really bad. I think if there was an outside legitimate company that came in and tested the air, the water, the facilities, I think it would be not shocking to us. Any test, anything that we have, our health and safety committee has demanded, always comes back fine. They are saying everything is fine, so if you disagree, I mean you can disagree all you want, but paper documents say everything is fine, so if there are issues, then it doesn't really matter.

Within Erica's narrative were indications that she struggled to reconcile discrepancies in information, the reactions of her employer, and her co-workers' experiential knowledge. Erica's standpoint was that risks for breast cancer were present in her workplace, but this perspective stood in deep contrast with the employer culture and dominant discourse, which either downplayed or disregarded these risks.

Annie also talked about the contrast in knowledge and power with her personal realities. "I was diagnosed the day after my birthday. I was shocked... I remember talking to my surgeon, and I said to him, 'I thought I was low risk,' and he kind of shrugged like,

'yeah.'" Annie tried to reconcile her doctor's indecisive response with her standpoint. She noted specific exposures she had had, seeing her experiential knowledge as observable truths she could trust despite the doctor's lack of acknowledgment. Annie questioned the dominant risk discourses and their capacity – or incapacity – to explain breast cancer risk factors.

Since my diagnosis, I have certainly met lots of people, and some that have none of the risk factors. I mean, the one is a long-distance runner, she is in excellent shape, she is a health fanatic. Like I just don't understand how people that are that healthy and low risk [get cancer], they don't fit any of those formulas for being at risk, so why do they get it?

As women reflect on their own experience, they face a sense of distrust of dominant discourses and specific information sources. Sara drew out a stark example of where traditional explanations of risk fail to explain what workplace exposures might when she reports knowledge of male co-workers at the Bridge with breast cancer. "I know at least of one incidence...there was another one possibly. But even just one guy! Even that's still just like, very, wow!" Sara's narrative conveys that her experience of risk was at odds with standard explanations for breast cancer development and point to her lack of trust in the dominant discourses and master narratives of breast cancer risk.

These narratives of breast cancer risk in the interviews I conducted with women who worked at the bridge illustrate how the shaping of the experience of breast cancer risk is influenced by social and cultural systems, where biomedical knowledge enters in, but where popular knowledge and personal experience are essential in the creation of "socially meaningful explanations" (Kleinman, 1978, p.89). For these women, the experience of managing knowledge of breast cancer risks requires assessing and discerning between seemingly distinct and different realities. The women combine knowledge from various domains in constructing their narratives, with expressions of their standpoint in the socioecological framework where health is experienced.

The narratives of risk reveal that women acquire and evaluate information from the multiple systems that interact in their subjective experiences and locations. Their stories illustrate how gaps, contradictions and dissonance between different systems become apparent as they contemplate risks meanings. The narratives the women construct are also sites of change, spaces where women intervene to make meaning and sense of the risks, attempting to reconcile the contradictions and overlaps of different knowledge systems.

## What Really Matters

The method of analyzing how women's experience and standpoint influence their breast cancer risk understandings is enhanced by using the lens of Kleinman's concept of 'what really matters' (Kleinman, 2007). What really matters includes both external and internal influences and sociocultural factors and impact people's moral decisions. The construction of narratives of risk understandings involves a negotiation of multiple sectors wherein decisions women make about jobs are not distinct from health decisions. Analyzing through the frame of what really matters brings out the nuances between conventional risk explanations' dichotomies, identifying the different ways women make breast cancer risk evaluations. What really matters to women influences and plays into their risk assessments. As a conceptual tool, it illuminates the constraints imposed on the experiences of women by dichotomous risk discourses and the ways women reconcile the multiplicity of risk factors related to risk in the spaces between the dichotomies. The lens of what really matters provides an understanding of women in their sociocultural contexts, expanding the bounds of risk knowledge translation that both responsibilizes and blames women for having certain kinds of risk knowledge.

In the narratives of the women workers from the Bridge, what really matters manifested itself for the women in such realities as weighing risk understandings with the job and financial security, protecting their health, harmony, and compliance. These concepts and considerations were not neatly organized as lists of priorities. Instead, they came out in the narratives containing the complexities of each story's totality, sometimes appearing as individual choices, but often as reflections of the wider systemic and structural influences on life. Women speak of these considerations, frequently in a somewhat circular fashion, revealing what really matters to them when dealing with their understanding of breast cancer risks.

Bonnie revealed her feelings about the conflict between health and the necessity of job and financial security. This conflict is another dichotomy and limitation imposed on women as distinct choices, as opposed to interacting elements in relationship with and one another. Both elements matter, but one appears to have to take precedent over the other. "When I first got diagnosed, it was like, why me? But you have to make a living [even though] it's not healthy for me to work here." She went on to say: "I was always proud to work for Customs. We had a lot of good times there, too. But it wasn't good for my family; it wasn't good for me. But it's a government pension. How can you turn that rate down? At least you know the last day of the month you'll be rich again (laughing). There's a pension, cash for life." For Bonnie, her moral imperative and what really matters were her family, her financial security, the joys, and pride she found in the job, and her future stability. At a time when women were just starting to get hired in greater numbers at the bridge, Sophia Belle's university education gave her an 'in,' There were numerous other benefits of the job that she highlights, illustrating that these things really mattered to her even when health issues began to affect her. "My parents were proud of me and always, always let me know. My mother was my biggest fan."

Mary emphasized that her family, financial benefits, and work/life balance mattered to her. "I don't love my job; I don't hate my job, which is good. It's a government job. I look at the benefits of everything, right? I have a great pension. I have got good benefits. I have got job security. I go to work, I do my job, and I come home. I don't ever take it home with me, and that's important to me. It's important for my family. It's well-paying." Fatima's financial security mattered to her despite the health risks. "I tried not to work too many midnights. I would if it was overtime, I believed in overtime, overtime was good, especially in my pocket." Kathy prioritized immediate needs and financial security: "It was a toxic environment to work in...but it was a good-paying job, so people put up with it. But it's not the healthiest place to work." Kimberly, a mother to young children, who had almost the same number of years with CBSA as Kathy and was aware of multiple breast cancer cases among her co-workers, noted, "Honestly, it's just job security, and at this point, it is difficult to find something that is equitable pay." Samantha said: "In my mind, I took that job as a very concrete means to an end, thinking I would only be there for maybe a year, and then I would resume what I thought was going to be my career path." Career mattered to Lily: "I saw a chance of advancement. And there wasn't a day that I didn't learn something, still to this day." Lily's breast

cancer diagnosis brought sadness at being "another statistic," but she admitted, "I think, well, it's a great job." What really matters depended on standpoints, which changed and shifted over time. What really mattered to the women is very much an expression of their location in their socioecological frameworks, as seen from their changing and evolving standpoint, a process of negotiating with the experiences of risk and life's complexities.

## **Conclusions: Spaces between Dichotomies**

Narratives of risk capturing women's standpoint in a socioecological framework are multifaceted. The narratives explain how women are often faced with a dichotomy: accepting genetics and lifestyle risk factors or environmental risks, of individual responsibility as opposed to the responsibility on the part of the employer or government to control risks for breast cancer; of voluntary and involuntary risks; of modifiable and non-modifiable exposures. Narratives reveal how women resist these dichotomies and develop their understanding of breast cancer risks more nuancedly. The nuances the women identify, explore, and explain, embody the spaces between the dichotomies.

The way women understand breast cancer risk is dynamic, contextualized, multisectoral, and relational. Women's insights into different spaces of understanding uncovered some common themes and concepts—information discrepancies, distrust, experience as knowledge, financial (in)security, harmony and compliance, health and well-being, career satisfaction—that are reflections of the sociocultural contexts in which the women live and work. Similarities and patterns of the concepts across the narratives provoke questions about the limitations of dominant breast cancer risk discourses. Beyond identifying themes and prevalent concepts, analysis of the narratives exposes the interrelationship between the knowledge women use to construct their breast cancer risk narratives and their environments. The knowledge sets and the ways they are presented from women's standpoint are a lens into sociocultural conditions and individuals' interconnectedness within their contexts. In other words, breast cancer risk is not merely a biomedical phenomenon, nor does it reside only within bodies. From women's standpoint, breast cancer risk is experienced as a nested set of relationships. The dominant cultural narratives tend to obscure the women's experiences, including many of the spaces where breast cancer risk is identified and understood.

The narratives bring out the conflict between biomedically framed risks for breast cancer and socio-culturally grounded understandings of breast cancer risk, particularly where environmental risks for breast cancer are concerned. The cultural shaping that influences women's experiences and understandings they incorporate into their descriptions are highlighted when they speak of their beliefs, expectations, roles, relationships, experiences, and values. Analysis of the women's understandings, as seen through their narratives, revealed that the construction of risks for breast cancer is reflective and an expression of their experience of risk as part of larger sociocultural systems that bring together knowledge from a multiplicity of sources.

Through the women's risk narratives detailed in this chapter, it is evident that environmental risks are a vital part of how they understand breast cancer risk. All but two of the women in the study considered environmental factors in relation to breast cancer in their narrative. Some women are very pointed about the connections, while others are more contemplative, making sense of information as they move through their narrative. When answering the initial interview question, "Tell me about yourself," many women expressed an environmental health consciousness. The significance of the environment related to breast cancer risks and knowledge and understandings of those risks varies widely, and the role of the environment at the Bridge was variable as the women spoke from their standpoint.

In the interviews, when we talked about the scientific literature on breast cancer causation, including known and suspected risks, and in discussions about breast cancer cases among women at the Bridge, some participants experienced a transformation in how they talked about risks. In particular, there was a shift in environmental breast cancer risk attribution. These moments emerge as spaces of critical reflection about the seeming dichotomies (White et al., 2013, p. 6) they face when considering breast cancer risks. The women's narratives bring out efforts to reconcile the spaces between the dichotomies. They are reckoning with what they find between the information drawn on and the understandings they produce from that information. In these moments of reckoning with risk knowledge, and in particular, the dichotomies, the women open up about what really matters. This is a process that, for most of the women, became a space in which they expressed a desire for more precise answers about breast cancer risks and for creating better working and living conditions. It also allowed for the filling in of gaps in the system that the women see as harmful to their well-being. Confronting the injustice that originates in some risk-bearing environments is also realized.

The transformative moments in the spaces between the dichotomies are emblematic of moral decisions made during these occasions. In the "space for critical self-reflection on our world and ourselves...we are morally responsible for ensuring that others understand the social injustice our worlds routinely create, including what we have brought about by our own actions." (Kleinman, 2007, p. 24). The women's moral choices in the face of knowledge of environmental breast cancer risks and the suffering, danger and injustice related to the risks reflect their values and the local realities of their experience and from their standpoint as women.

Distinct narrative typologies (Frank, 1995) are identifiable in breast cancer risk stories for women at the Bridge. Broadly speaking, when analyzed, the women's narratives of breast cancer risk reveal the spaces between the dichotomous characterizations of breast cancer risks, between non-modifiable risk factors (e.g., genetics, family history, income, etc.) and modifiable breast cancer risks (e.g. behavioural choices such as smoking, diet, exercise). Modifiable risk factors for breast cancer are further dichotomized when described as either lifestyle or environmental risks. The spaces between are evident when examining the women's narratives as they describe the understandings of breast cancer risks and the systemic complexities of modifiable risks. As the women construct their risk narratives, they expose the limitations of dichotomizing breast cancer risk approaches—something the medical system has done for decades. These narratives exemplify a typology I define as *Spaces Between Dichotomies*.

The fundamental understanding that is produced here is that the experience of breast cancer risk is a complex relationship between the individual and the broader social, political, and discursive contexts within which they are realized. Understandings of risk are both cultural and social. They are "not simply systems of meaning and behavioural norms, but those meanings and norms are attached to particular social relationships and institutional settings" (Kleinman, 1978, p. 85). This knowledge of how women, from their standpoint and in their socioecological context, understand and integrate environmental knowledge within their narratives can be used to facilitate the development of better and new approaches. Strategies for knowledge translation, knowledge mobilization, regulatory and policy modification and creation, risk mitigation strategies at the individual and collective level, and in setting priorities for future research investment are assisted by this knowledge. Importantly, these goals can be approached with the knowledge gained from women's rich narratives nuanced accounts of how women acquire, interpret, and value various knowledge pieces. This understanding can contribute to creating health policies where women are equal and contributing partners in health promotion.

The understandings and conclusions produced are manifestations of core adaptive tasks (Kleinman, 1978), including acknowledging the cultural construction of illness, the cultural construction of strategies to evaluate the efficacy of health decisions, and the cognitive and communicative processes that provide personally and socially meaningful explanations in the management of health. These tasks illustrate the multiple interacting relationships and levels of the socioecological environment wherein health is a function. Recognizing women's narratives of risk for breast cancer, where they are rooted in cultural systems, and importantly including the spaces between the dichotomies, identifies gaps in breast cancer risk discourses and the relationship between those gaps and strategies for risk mitigation rooted in the same cultural systems.

Culture, medicine, and structure influence the experience of risk and narratives that describe those experiences. Therefore, "thinking about this as an ecological challenge helps us identify multilevel interventions that will reduce breast cancer risk and improve outcomes" (Schettler, 2014, p. 16). A critique of women's material relations emerges when examining the women's breast cancer risk narratives as critical pieces of knowledge in understanding breast cancer as a social phenomenon. Embracing the women's standpoint, recognizing their knowledge as socially situated and therefore specific, gives voice to their traditionally marginalized perspectives by focusing on where and how inequities in breast cancer risk control are experienced (Smith 1974, 1987; Collins, 1986, 1990).

In the next chapter, I examine the last of three research questions: who has control or agency over risks as shaped in the women's narratives.

## **CHAPTER SIX**

#### Narratives of Agency: Transcending the Implication of Individual Volition

Sarah, living out her retirement in Windsor, Ont., reflected on more than three decades working for CBSA at the Ambassador Bridge. She spoke of the variety of experiences and expertise she acquired over her career. Her stories provided detailed descriptions of the bridge environment, the working conditions and practices, and efforts made over the years to address risks she and her co-workers identified in their jobs. Perhaps due to her educational background in sociology, Sarah's stories of struggles for mitigating breast cancer risks and other health and safety problems at work are infused with an analytical lens. She addresses power and structure not just in the workplace but in society more broadly. Her standpoint suggests the struggle to reduce exposures to breast cancer risks is a multi-level problem:

It has to be people, grassroots; people banding together and pushing governments and politicians because you have to get awareness on the issue and the problem. You have to push the governments and politicians to have awareness of the issues and to get it up there to the highest level. Because it's not going to happen on its own. The government isn't just going to take it upon themselves. It's really rare.

This chapter's focus is on answering the last of the three research questions for the study: How do the women perceive and exercise agency in the context of breast cancer risks? In this chapter, I consider how women place agency in their narratives. I also discuss and analyze how agency emerges in the women's narratives in response to the related interview questions, including most importantly: *Do women have any control over their breast cancer risks or are there others who might have control over risks for breast* 

*cancer*? (see Interview Guide, Appendix A). This chapter explores and analyzes how women's narratives draw out agency regarding risks for breast cancer. In keeping with the theoretical framework, the analysis applies Kleinman's approach of locating subjects in their cultural systems and recognizing that women's understandings of risks are mediated through their (feminist) standpoint within socioecological frames wherein material realities produce disparities in power relations.

## Agency and Adaptive Tasks

Agency, simply defined, is the willful thoughts or actions taken by individuals (Scott, 2014). The history of the treatment of the concept within sociology contains debates about agency's nature, with the roles of the individual and structure problematized in these debates (Bourdieu, 1977; Giddens, 1984; Alexander 1984). Agency is sometimes treated as though it were in a dichotomy with structure, often linked to class and power dichotomies, where arguments follow that agency is enabling, whereas structure is limiting. Therefore, agency is frequently conceived as individuals acting in response to social structures or opposition to those structures. These actions can be individual or collective in nature. Emirbayer and Mische, in their 1998 paper "What Is Agency," define agency as:

a temporally embedded process of social engagement, informed by the past in its iterational or habitual aspects, but also oriented toward the future as a projective capacity to imagine alternative possibilities, and towards the present as a practical-evaluative capacity to contextualize past habits and future projects within the contingencies of the moment." (p. 962) Kleinman's concept of adaptive tasks parallels Emirbayer and Mirsche's definition of agency (Kleinman, 1978, p. 87). Adaptive tasks (described in Chapter Three) are cultural and psychosocial functions that inform and influence the construction of strategies and evaluations guiding health choices, health-enhancing and preventive behaviours, and the management of outcomes related to health. Following these definitions, this chapter and analysis conceptualize agency as thoughts and actions understood and experienced at the individual level and rooted ecologically, including temporally.

Apprehending agency as ecologically embedded challenges and upends the dichotomies associated with breast cancer risks. The dichotomies fail to capture women as full participants in the social world and processes and ignore the roles that women play in both reproducing and changing social relationships. Through the definition of agency and the lens of feminist standpoint applied here, women are recognized as agents in the development of risk mitigation strategies, including and importantly, through the production of narratives as a form of agency in the larger project of breast cancer risk mitigation and primary prevention strategies. Agency, as seen this way, recognizes women as individuals in relationship with and part of the structure.

As articulated by the women through their narratives, agency includes the meanings they construct, as well as actions and strategies they talk about as possibilities for control over breast cancer risks. Adaptive tasks in the interviewee's narratives incorporate knowledge and understanding of the cultural system they encounter and identify systemic and institutionalized conflicts. These conflicts illustrate barriers to breast cancer risk mitigation in their workplace and broader sociocultural environments. From the women's standpoint, as seen through their narratives, the interrelationships of societal structures in the socioecological model are crucial to understanding how agency is, or could be enacted, as adaptive tasks in response to environmental breast cancer risks.

Agency is examined through the various methods of controlling breast cancer risk factors the women believe they face in their lives and the context of their work at the Ambassador Bridge. When described in the narratives, breast cancer control is more than biomedical knowledge or scientific evidence of breast cancer risk; it is expressed as a problem of context and the lived experiences of the social and cultural systems in which they are situated. As the women talk about control over breast cancer risks, they cultivate critiques of existing systems for addressing breast cancer, applying the circumstances of their experience to larger knowledge sets as constructed using understandings beyond themselves. In that sense, agency is not just about material action but is also conceptualized as advancing the idea of adaptive tasks and adaptations conceived of and potentially enacted within socioecological contexts where standpoint provides the impetus for their conception.

As discussed in Chapter Three, conventional assumptions about breast cancer and risks for the disease suggest that agency directed at health-enhancing and preventive behaviours are to be carried out by women as individual lifestyle choices. Traditional and mainstream messaging reinforces the individualized focus while omitting or casting uncertainty about environmental and workplace changes and social policies. Analysis of the women's narratives reveals that women begin to break open these assumptions while incorporating other ways of knowing, being and enacting change. Agency, as conceived of by the women in their narratives, is identified in both personal life and work life, not as unrelated, independent ways of thinking, but rather as integrated and interdependent. As described in women's narratives, constraints on agency occur institutionally, in the workplace, in discourses, and ideology, specifically within neoliberalism. Despite these identified constraints, the women derive a multiplicity of ways of becoming agentic, conceptualizing health agency and adaptive tasks in response to questions of control over breast cancer risks in an ecological framework and nested relationships.

## Locating Agency in Women's Stories

When speaking about what could be done to address the risks for breast cancer in the bridge environment, Sarah had numerous suggestions—from individual-level behaviours, modified workplace practices and policies, to legal and regulatory changes at the government levels. She responds to the questions about control over breast cancer risks in a way that makes it clear she believes change is a process that requires activity from the micro to the macro level of the sociocultural and institutional systems. "Somebody has to start it because the government is not going to start it on their own. They're not going to say, "oh yeah, we're going to do this because we're nice. It needs to start from people, a movement."

Sarah's prescription for change is part of her broader narrative of breast cancer risks, constructed from her knowledge gained from her education, medical and other academic journals, health and safety reports at work, multiple media sources and, importantly, her own experiences. Her observations mirror the socioecological framework where there is an interconnectedness of individual, social, cultural, and political systems, Sarah's standpoint incorporates internal and external factors, grounding her "beliefs and activities in socio-political structures and in particular local environmental settings" (Kleinman, 1978, p. 86). While Sarah's narrative addressed some of the complexities of enacting agency in a multi-level structural system, Kathy's standpoint is reflected in more straightforward terms and shows she sees herself as an agent of change in environmental risks of breast cancer. "I truly believe that the environment has a huge part [to play], and I would like to do something about [it]."

The narratives of Sarah, Kathy, and others illustrate what they believe about how and where agency could be enacted, as well as barriers to agency. The women do not use the term "agency," but their descriptions of their understandings, beliefs and experiences function to identify them and others as agents of change. Furthermore, while the women recognize inherent power disparities across relationships, institutions, and systems, and that there are limitations to individual actions, their narratives suggest the participants can alter, or imagine they can alter, social realities and societal structures. Thus, as Sarah and the other women talk about control over breast cancer risks, they reinforce the idea that agency is not a dichotomy with power. Agency and power are understood as interacting with one another in the relationships of a socioecological framework. In this framework of interactions where power is intrinsic, women both reproduce and challenge existing power relationships. Correspondingly, women reproduce dominant ideas about control over breast cancer risks, and they also challenge them through the experience of their standpoint.

#### **Personal Strategies**

Agency around breast cancer risk mitigation for the women I interviewed focused in some instances on strategies they could undertake at the individual level. The strategies include embracing personal behaviours in day-to-day life and modifying personal practices at work that might minimize exposures and prevent breast cancer. Sometimes the women wholeheartedly endorsed these behaviours, and other times they adopted them with a sense of doubt as to the efficacy of their actions.

A CBSA employee for close to 20 years, Kathy said, "I didn't know a lot about lifestyles back then, but there has just been so much more brought to light with that, you know? I think you can decrease your chances [of breast cancer] by the lifestyle that you choose and what you expose yourself to." Her words suggest she perceives breast cancer risk factors are personally controllable but went on to say, "Genetically, you can't fight that. It is what it is." Kathy then described risks at work that were outside her control, "You know with the x-rays [of the cargo] and that kind of stuff; I am sure that's a risk too, but there are risks at every job, I'm sure." Her standpoint seems to reinforce occupational risks as taken for granted and personally unmodifiable. Kathy talks of the multiple levels of risk factors, trying to reconcile them, illustrating the interplay of the sectors in sociocultural frameworks and how the relationship between them leads to overlap in personal, biomedical, and cultural understandings of risk mitigation.

Julie, whose information about breast cancer risk includes personal, popular, professional, and folk sources, talks about health-conscious decisions made for herself and her family such as eating organic food. When she talks personally about health decisions, Julie also provides a glimpse into the workplace's practices and culture and the impact they had on her personal health agency. She describes the institutional expectations understood within the workplace, the culture around work ethic and rigour as it exists within the women's internal psychosocial and communicative processes, including the sadness and empathy they felt for one another. "There would be a couple of girls off for a while, and you wondered, 'Oh, they are off. What is going on?' The shared emotions show that affect is a collective experience and a powerful component of shaping what women see as possible, and yet another example of how agency can be understood in the women's narratives. Observations and descriptions infused with personal emotion about the working conditions and environmental exposures as harmful to themselves, as well as their fetuses, their children, and their male co-workers, were common in the women's responses to questions about exercising control over risks.

There is an emotional component to Annie's narrative of the conflict between personal strategies through lifestyle choices as seen through a biomedical lens, contrasted with the cultural and other external conditions she faces. Here, agency is illustrated in the internal processes about limitations of personal actions and external factors she sees as beyond her control, constraining her agency.

The air that we breathe, I don't feel like I have any control over that at all. Especially because I think a lot of our pollution is from the States, so it isn't even like I can lobby our government to change things. And I certainly can't lobby the American government agencies to change things.

Annie incorporates social and cultural knowledge into her standpoint on personal agency. "I think that there is almost a defense mechanism where I concentrate on what I can influence rather than what I view as all but hopeless for control purposes." Annie shows her understanding of systems of governance and regulation and how they function on the institutional and political levels, combined with individual action, as she interprets avenues for agency. Her narrative signals how culture influences the construction of strategies and evaluations that "reveal the nature and extent of historical, political, economic, technological and epidemiological influences on health care" (Kleinman, 1978, p. 91) as multiple levels of a nested set of relationships (Schettler, 2015). Resolving discrepancies between the processes within the system is a function of agency produced in the women's narratives and the interplay between internal "psychosocial, behavioural and communicative" processes and external "social, political, economic, historical, epidemiological and technological" factors (Kleinman, 1978, p.86)—all of which factors converge in the experience of risk and agency as described from women's standpoint.

Dana, born and raised in a farming community, spent twenty years in Windsor raising her family. Enthusiastic and optimistic, it was evident she cared deeply for her family, her co-workers, her community and herself. Dana pointed to pesticide use on lawns and other "chemicals we use in our daily lives" as contributors to breast cancer risk and said, "At my house, I minimize as much as I can and use the environmentally friendly products." Dana spoke about personal agency as something she also exercised at work: "I try to avoid as much diesel emissions and things like that as I can...It's kind of preventive per se. Like I said, there is a predisposition for some things, genetics, and things like that. But I really do think diesel emissions is a huge factor." Though Dana talks about protective efforts as personally modifiable exercises she undertook while working at the bridge, she says some of her co-workers were otherwise occupied. "Some staff, I don't think they really think about it. I think they are so involved in their job, and they just want to get [bridge] traffic down and make sure everything is running smoothly." Dana's explanation situates decisions workers make in the context of the expectations and pressures at work, prioritizing the job and placing institutional needs over individual well-being. The prioritization of duties was not an uncommon refrain in the narratives. A sense of obligation to the job, traffic flow, goods crossing the border,

and keeping the economy running are cultural priorities at the bridge and beyond, and these matters were prevalent in the narratives.

Another factor influencing women's agency and choices they see available to them was institutional culture and values. This phenomenon is reflected in Bonnie's narrative:

The biggest thing is to keep the border going or moving... there were a lot of studies being done for health reasons from shift work, so we had brought those up and tried to make it better. So, we did do that to try and improve things for health reasons. It's the busiest border crossing in the country. You can't get away from the fumes.

Bonnie's words illustrate that agency on risk mitigation could be realized through personal health-protections but were imagined within the frame of the workplace culture and institutional factors, as well as broader sociocultural influences, including the economy.

Larissa, with a background in criminology and security, is a strong advocate for women. She recognizes personal lifestyle choices are a method of control over breast cancer risks. However, like many others, she is not convinced these strategies will have any effect given her broader context for exposures. "I try to do those things [exercise, eat healthily], but again, it is hard not to have that inevitability, where you are like, 'Ah, I am going to get cancer anyway, so why go the extra effort?' It's hard not to do that. I am breathing in diesel fuel for twelve hours a day. Really, is this going to help me? But obviously, I do things." The socioecological framework of interconnected sectors is incorporated into Larissa's standpoint as she imagines systems interacting through her risk narrative. Personal strategies, including behavioural choices around diet and exercise, and external factors, including the workplace's social and economic factors, are integrated, and combined.

Mary's standpoint suggests there is no amount of personal agency that would change conditions putting her at risk for breast cancer. "I don't know if anything could ever be done...." Her perception of her agency with regards to mitigating risks is nested in the institutional and wider economic culture that she sees as constraining her agency. She pointed to the bridge's operations, hoping that there was not a cost to her before she would finish out her work there. She said, "They are not going to shut the border down. Realistically that will never happen. I just hope with time that I can leave that part of the job behind and move on." For Mary, agency comes with an awareness of the complex processes at play, the possibilities, and the limitations built into her health's systemic cultural influences.

Bonnie speaks of agency in temporal terms, reflecting on things they attempted as a workforce, personal efforts, and other possibilities. Her narrative contains recognition of the limitations on agency within her workplace context. "We did try and improve things for health reasons," she said. "The fumes—it's the busiest border crossing in the country. You can't get away from the fumes. I always have them shut off their truck. Cars not so much. But then is it worse when they start them up." Her behavioural choices were made within a social and institutional context, which shaped her agency. "We were getting better booths. As a facilities officer, we worked on getting better booths and better glass. But there is only so much you can do," she said, conscious of barriers to agency. I don't know if it's a crapshoot. If I am going to get cancer, I am going to get cancer. I can do things that I think are going to help me to eat right or be healthy, but my work environment, you can only do so much. If I have to work, then I have to work there. There is nothing I can do.

Bonnie's narrative suggests a relinquishing of control on her part, recognizing that some things are beyond her influence. Larissa's standpoint also conveys a sense of powerlessness. "Absolutely [it feels out of my control]. I mean, there are obviously things we can do, and I am not going to say that our employer doesn't provide certain [things], or our health and safety [committee]. I am not saying it is a completely lost cause. And I have the ability to say if I find this to be unsafe, I can stop, in theory. Does it happen in reality? No." Larissa suggests that leaving the Bridge is a way to exercise agency over risk, couched in a hesitant acknowledgment that change was still possible in the context of the workplace and institutional structure.

Leaving the bridge is an obvious form of personal agency—and a form of agency that is also a method of resistance—mentioned several times in the 25 interviews. It is a personal choice that some women see as available to them, while others see it fraught with multiple issues that limit or preclude them from leaving their jobs. In this sense, these choices become moral decisions where *what really matters* enters into the equation. Although personal strategies are essential and are prominent aspects of the women's narratives when discussing agency in response to the question of control over breast cancer, there are limitations, including economic and employment, to their personal actions from the standpoint of the women. Descriptions addressing agency concerning breast cancer risk illustrate the women make evaluations about the effectiveness of personal strategies beyond individual conditions and circumstances. The women evaluate health decisions and therapeutic efficacy at "physiological, psychological, social and cultural" levels (Kleinman, 1978, p. 87), nested in systems and structures, consistent with such interactions as illustrated in the socioecological framework (Bronfenbrenner, 1977). While addressing personal strategies, the women conceive of agency as more than individual actions, identifying workplace systems and cultural influences contained by wider structures.

# Workplace Strategies

The multiplicity of the strategies for breast cancer risk mitigation raised by the women at the bridge drew on knowledge and understandings of their workplace and the broader sociocultural context of health and social systems where agency could be imagined. The women's agency considerations in the workplace reflect cultural influences, including conflicts "between biomedical and social realities through major social and political change" (Kleinman, 1978, p. 91). The women express workplace strategies for risk mitigation in their narratives through illustrations of social and administrative transformations through workplace action, health advocacy and institutional-level agency and how these are shaped and constructed by and within nested social and cultural systems. "There are things that we can do," said Larissa. "If our job breeds [breast cancer], then we need to nail down the risk factors and work at changing our exposures to those."

Cindy focuses on knowledge as a foundation for taking action in the workplace. "I feel that if people have the knowledge that maybe we need to start pushing back a little

bit," she said. "We want better infrastructure; we want whatever [is needed]. But we could probably move that forward if we had some research and evidence that we could bring into our management." Cindy was optimistic as she imagined political, cultural, and social systems as sites to enact agency. "Sometimes, you just need someone to plant the right seed about things."

Like Cindy, Lorraine also pointed to increased knowledge as a pathway for agency. She incorporated awareness of workplace cultural priorities in her risk narrative. "Safety is probably more of a priority than health [at work]. It is time for health. I think all it takes is more knowledge about the health [risks] so that they know what is going on." Lorraine's awareness of social and cultural system values across sectors informed her standpoint when she said, "I know we are not all scientists; we are not doctors, we don't know these things. But if it is put in a format where we understand the consequences of our health because of these factors, like the air quality, then I think that is something the union would be able to work with." Mary inferred that current knowledge gaps and inaction would continue to put women at the Bridge at risk for breast cancer. "Ignorance is not bliss. It doesn't make everything better." She recognized agency was a complicated product of cultural systems, where interactions and transactions occurred between individuals within structures.

Envisioning agency materialized in the women's narratives through information and understandings of specificities of the Bridge, related exposures, and temporal and societal changes; for example, increasing truck volumes resulting from justin-time shipping, and long periods processing trucks and cars related to post 9/11 increased the rigor of inspections and greater securitization of cross-border travel. These conditions led to women's perceptions that there have been increased exposures, along with more breast cancer cases and other health problems. They described potential infrastructure changes that could address these problems. Lorraine's narrative brought out the complexities of the women's working conditions:

I think we all know [diesel fumes and poor air quality] is there. It's just, what can you do about it? Not too much. The port is going to run. We need another bridge, is what we need. Air quality is bad. I don't know what the solution is there, but it's definitely something that has gotten worse over the years because I don't think that Bridge was built to encompass that traffic and now that it is, I think a lot more people are getting sick. I think there must be some connection because too many people are getting sick.

Lorraine contemplated improved policies and practices at the future Gordie Howe Bridge<sup>7</sup> as she discussed her understandings of the shifting economic, political and trade contexts that influence traffic volumes and related exposures. She pondered possibilities of infrastructure improvements and engineering considerations for the bridges and the trucks: "What would you do? Or how would you fix it? They are going to build two more bridges. Maybe they have to limit the amount of trucks on each one, space them, so it's not so congested in one spot. Plus, maybe then they can work on how these trucks are

<sup>&</sup>lt;sup>7</sup> The Gordie Howe International Bridge is a public-private partnership (P3) project. The Gordie Howe International Bridge is a 6-lane cable-stayed bridge, 2.5 kilometres/1.5 miles in length with a clear span of 853 metres/0.53 miles. The Canadian Port of Entry is an approximate 53 hectare or 130-acre site and will be the largest Canadian port along the Canada-US border, and one of the largest anywhere in North America. It includes inbound border inspection facilities for both passenger and commercial vehicles, outbound inspection facilities, toll collection facilities, a maintenance facility and parking. On October 5, 2018, WDBA and Bridging North America officials were joined by the Prime Minister of Canada, the Minister of Infrastructure and Communities, and the Governor of Michigan for the official start of construction of the Gordie Howe International Bridge project.

<sup>(</sup>https://www.gordiehoweinternationalbridge.com/en/project-overview).

built." Lorraine's narrative accounts for multiple levels and influences on and of the systems that interact. "Those are concerns that they might like to start with. The actual truck might be something where they can fix it. They are always fixing vehicles to become more energy conserving. They should be looking at maybe health-wise how you can fix these pipes, so the air that comes out isn't like that." Her solutions, the adaptive tasks she suggests, "relate sociopolitical and environmental determinants to biological and cognitive processes" (Kleinman, 1978, p. 89), recognizing the nestedness of agency within a socioecological framework. Agency reflected this way moves towards a greater vision of social change beyond the individual and the workplace to broader society.

CBSA employees, as members of the PSAC-CIU,<sup>8</sup> have union and joint unionmanagement health and safety committees as avenues for addressing workplace issues and concerns. Many women spoke about union experience as members of the health and safety committee and knowledge of past successes, challenges, failures of the union and committees to address specific problems. The inability to adequately address perceived risks for breast cancer and the cluster of breast cancer cases among their colleagues was voiced. The women also discussed general job training and health and safety training, suggesting possibilities of exposure reduction strategies within those frameworks.

Cindy recalls her training: "I got hired when I was 26, and they literally never brought up health issues whatsoever," she said. "Our hearing, the fumes that we were breathing, shift work, nothing. It was just never addressed, at all, in any of our orientation." Cindy felt that this was a gap and required improvement. She also suggested that monitoring exposures and health markers for breast cancer could be implemented.

<sup>&</sup>lt;sup>8</sup> PSAC-CIU is the acronym for the Public Service Alliance Canada – Customs and Immigration Union, the unions that Canada Border Services Agency employees are represented by.

"We had four months of training, and I would love—now that I think about it because I have twenty-seven years in—I would love for that to be part of what a new hire finds out about. Years later, they started doing hearing tests on us on a regular basis, but that's it."

Sophia Belle, reflecting on her experience with breast cancer, said, "I do wish for changes for the current staff, and I hope that they would be willing to step up and become a part of this because they won't have twenty years or forty years of waiting time to get sick. It will happen sooner rather than later." She believes the union could do more to address the women's workplace risks for breast cancer. "Unions have to be far more proactive in getting involved, and I believe they are" Like Sophia Belle, Cindy is optimistic about the direction the union could take and described the structure and agency of the union and the health and safety committee as evidence of these possibilities. "We have a health and safety committee that is made up of the union and management, and they meet regularly and talk about these kinds of things and things that we can do to make it a safer workplace. To me that it is the way to go because those people have standing with management." Cindy's knowledge of the institutional structure informed her strategy. "If that [health and safety] committee member brings something up, they are legally obligated to address it." The interaction between legal and institutional frameworks and the individual in the system is incorporated in the narrative. "The health and safety committee is the one who brings out those boxes that get the air [samples]. If it's just a group of employees, then it will be easier for them to just brush it off. If the health and safety committee brings it up, they have to address it. They are obligated to."

Cindy's awareness of the system's levels of interactions, the strategies possible within the existing structures, and the barriers to agency she identifies are illustrative of the complexity of internal and external factors and her understandings of where control over risks for breast cancer is socially grounded. She understands the extent of the responsibilities and reach of the health and safety committee and demonstrates knowledge of the multiplicity of interactions for addressing breast cancer risks produced by Ambassador Bridge conditions and practices. She also recognizes the social interactions and the hierarchies involved in these activities, the varying responsibilities and obligations of the parties involved, and the role that technical information could play in these dynamic relationships.

Among the discussions where agency emerged, the strategies women mentioned included further awareness, knowledge, and information mobilization of breast cancer risks through all levels of the system; improvements in infrastructure, including the layout and location of the workplace with specific mention of the future Gordie Howe Bridge. Women also talked about engagement through management, the union, and the joint health and safety committee; enhanced training and policy; liaising with physicians for better patient education; tracking of work histories for women at occupational risk for breast cancer; facilitating fair adjudication of breast cancer claims through the Workplace Safety and Insurance Board (WSIB); increased attention at the level of governments, including inspection, policy, legal and regulatory change; and influencing company policies, priorities and practices. Each of these strategies represents reflections for action beyond individual and personal actions, grounded in the knowledge of the workplace's cultural context and institutional structures. The strategies are both constrained by and made possible by the institution and workplace culture and systemic knowledge sets.

# Health System Strategies

From the standpoint of the women I interviewed, the health care system, inclusive of the roles, interactions, and transactions within the medical sector, was a site for enacting agency around women's breast cancer risks at the bridge. The widely held belief among the workforce that vehicle exhaust, air pollution, radiation and shift work may be associated with elevated risks and incidence of breast cancer contributed to incorporating the health care sector and the actors within as agents for change. Cindy foregrounds the role of the relationship between the medical sector and the workplace: "[For] the female members that we have, get some literature and say 'Here, think about this; tell your doctor where you work; tell him what you are exposed to,' so that when you talk about your health every year when you go for your check-up, it's something that you are thinking about." Cindy highlighted informational transactions between the women and their doctors to increase awareness in the medical community of the potential workrelated illnesses and diseases the women at the Bridge face. This would also help establish baseline medical documentation for individual women, contributing to a largescale and long-term recording of occupational health and safety conditions, representing a potential future data source for breast cancer's etiology. The life-course perspective and shared agency are integrated into Cindy's insight.

Fatima also saw the value of health monitoring over time. "I think when you start [at the Bridge], you should go for a baseline medical on everything," said Fatima. "Hearing, sight, your lungs, breast cancer, whatever. And then [again], like five or ten years later, you know, every so often, and look at the health problems." Lily also envisioned an ongoing relationship between the women workers and their physicians. With breast cancer or any kind of cancer, if you started and you were healthy, and everything was fine and then all of a sudden [you have breast cancer]. They know that working at the border or working in Windsor can cause breast cancer. Then if your doctor knows, let's do some checks and balances. People with heart conditions that run in their family, they get tested at an early age to make sure everything is fine and then they are monitored throughout their lives. The same thing should happen.

Lily pointed to gaps in the health system that could be rectified with the inclusion of knowledge and practices on occupational breast cancer. "I think it is one of the gaps that we are experiencing, that the medical system doesn't have our jobs on their radar." She suggested that brought out the shared agency for workers and health care providers. "When you go and see your doctor, you need to let them know where you work. And then there are checks and balances that the doctor puts into your well-being along the way. So that there is a record." The "record" Lily refers to could be a manifestation of agency via institutional features interacting with internal processes to address breast cancer risk for women in risk-bearing environments.

One of the complexities of the relationship between workplace exposures and women's health was described in stories of the difficulty dealing with the Workplace Safety and Insurance Board (WSIB)<sup>9</sup> not only around breast cancer but other work-related health issues. The intersection of the health care sector with the WSIB has

<sup>&</sup>lt;sup>9</sup> According to the Workplace Safety and Insurance Board (WSIB) website: their responsibilities and duties are, "When an injury or illness happens on the job, we move quickly to provide wage-loss benefits, medical coverage and support to help people get back to work. Funded by businesses, we also provide no-fault collective liability insurance and access to industry-specific health and safety information. We are one of the largest insurance organizations in North America covering over five million people in more than 300,000 workplaces across Ontario." (https://www.wsib.ca/en/about-us)

become difficult terrain. The WSIB is historically gendered and tends to downplay gendered inequities in injury and disease (Storey, 2009). Many women see a longstanding and continued struggle to obtain WSIB recognition of the relatedness of workplace exposures with breast cancer development as a miscarriage of justice and a failure to recognize the science of occupational exposures (Gilbertson & Brophy, 2018).

When women discussed the denied WSIB claim by their co-worker for breast cancer, they framed it with descriptions of feeling that their breast cancers and other illnesses and injuries were met with doubt and subsequently diminished. The procurement of timely disability payments was one of the implications of this problematic relationship. Lily said, "There should be the moment that they say you are diagnosed with breast cancer, you are going to be off more than thirteen weeks, so you are going to have to go on disability. So why is it that we have to go [apply for it]? That is what stressed me more than anything else, having to wait." The inability to readily retain financial security in the face of diagnosis is frustrating. "I still have to live. I still have a mortgage to pay. What about those who are thirty years old and have children and their husbands don't have the engineer's job or whatever?" Lily's awareness of the institutional culture and structural influences are evident. As described by the women, the problem is the institution of the WSIB, reflecting a broader culture that ignores the needs of women and workers in the wake of a breast cancer diagnosis. Lily's solution is to challenge that culture to create a shift where women's work and health are recognized as connected through medical, legal, and other institutional frameworks. Many of the other women shared her sentiments.

Lorraine said: "You feel like they [WSIB] are against you. You don't feel like they are with you, to help you, and that's a shame because they are supposed to help you. That is what they are there for." Mary described how the WSIB could be a barrier to efforts to connect workplace exposures with breast cancer. "I had to deal once with WSIB. They are extremely difficult to deal with. They will try anything to not have to pay you. I can imagine trying to deal with WSIB regarding something as broad as breast cancer. That battle would be never-ending." Despite problems in wait times for disability payments, delays in having compensation claims accepted, disputes faced on workrelatedness of illness and injuries; challenges in the transactions between doctors, employers and WSIB for accommodations, the women at the Ambassador Bridge still believed the WSIB and the disability insurance system were sites where they could achieve agency directed at addressing occupational breast cancer. "I don't think it ends at just breast cancer," Erica said, "I think there are going to be other cancers and health issues that it [compensation] would open the door up to." The women's narratives related to agency within health systems, including compensation, illustrate challenges of resolving conflicts between cultural systems, highlighting the "systemic relationships" between the components" (Kleinman, 1978, p. 86).

# Structural Strategies

Structural changes aimed at policy, law and governance were areas of agency that were fundamental to the women's narratives. Their multi-level approach in imagining theirs and other agency on breast cancer risk reflects a socioecological awareness and the nestedness of health relationships (Bronfenbrenner, 1977; Schettler, 2015). Structural strategies discussed by the women illustrate their developed understandings of how systems are political. The women's narratives pointed to structural based strategies, and they demonstrate they see their workplace not merely as a place of employment but as a set of systems and ideas that produce obstacles and conflicts. Gender was a factor identified in these reflections. The identification by the women of multiple sites where conflicting perspectives on the issue of control over breast cancer risks existed, including with governments, employers, and employees, exemplified how women recognized their standpoint embodied important contributions to resolving the conflicts.

As we discussed control over breast cancer risks for workers at the Bridge, several women highlighted government-level action and shifts in approaches. Kathy turned to past examples of interventions with Labour Canada, the federal regulatory agency responsible for occupational health and safety at the Bridge. She also pointed out obstacles that might impede meaningful action, doubting they would be willing to address workplace environment risks. "I don't know as far as the environment if they could do air testing and that kind of stuff. I am sure they can. But would they come down?" Her perception was that governmental oversight was not working in the women's favour, and the institutional culture of the Ministry favoured not responding to the health concerns of the workers. The cultural complexities and unknowns that Kathy alludes to are inherent in a system trying to reconcile biomedical knowledge with cultural values.

Like many others in their narratives, Lindsay tried to bring information from biomedical and cultural sectors together in her expression of agency she thought appropriate for breast cancer risk mitigation at the Bridge. She looked beyond herself to structural solutions with knowledge of cultural and historical context.

172

I think we bring it back to mitigating the risks from an employer perspective, or even government. I don't know so much what the government has done to mitigate the risks of breast cancer. And I think based on the research, they could definitely do things similarly to mitigate the risks of breast cancer, such as they have done for lung cancer.

Janis also identified a government role, proposing regulatory and policy changes. "I think the government should step up and make companies change." She spoke of imposing exposure limits and changing practices. Kimberly's standpoint on government was straightforward. "There is a level of responsibility that falls on the government. I do feel that the government should be held accountable. You can't tell me they don't know what is going on." Erin, too, addressed policy, bringing back awareness as the starting point, saying, "I think that awareness is needed. I think that ensuring that people have the knowledge of what is going on is a really big issue, and then, with the knowledge, the ability to change maybe policy or the way that things are being done. So, pollutants and different things are not as prevalent, or removed altogether, so that people are not at risk."

Annie squarely places responsibility for action on breast cancer risk mitigation by governments. "I am a big proponent of government taking care of us citizens. To me, that is what government is for. So, a smaller government, I am not so much into that." Her observation provides a counter to dominant neoliberal cultural ideas and attitudes about government, including accusations of paternalism. "Regulation is important to me. I feel that that's key for taking care of our citizens." Annie's standpoint also drew on cultural knowledge of government institutions. "I would like to see more regulation, properly developed. There need to be more evidence-based decisions made by government,

173

especially for women's health issues, Health Canada and the Ministry of Health and so on." Annie's narrative reflects her knowledge of the nestedness of breast cancer at the Bridge within broader social, political and structural levels, recognizing the systemic nature of the problem. "We could all write to our MPs or call them. Petitions, letterwriting campaigns, it is sort of old school, but if it is done on the social media platform, then maybe that would work." Annie is emphasizing how individual agency is interrelated with governments' agency.

Imagining agency as a philosophical exercise emerges in Samantha's thoughts "There is something very life-giving in just standing up for life even if ultimately you don't succeed in overthrowing the regime. Just lending your voice to the opposition is the victory. No matter how small it might seem, there is something very noble to me about that. When you choose to see life that way, you start to see everything that way." Agency and core adaptive tasks seen through structural strategies in the women's narratives incorporate knowledge and understanding of the cultural system and institutionalized conflicts (e.g., insufficient regulation, lack of government responsiveness, and relative powerlessness of workers). Although the women perceived structural barriers, their standpoint led them to understand the interrelationships in a socioecological framework, producing sophisticated ideas about how agency should be enacted in response to breast cancer risks in their environments.

#### **Agency Reflected through Moral Priorities**

Entering into an understanding of what matters to women from their standpoint, foregrounding their subjective knowledge situated in local environments, provides insight into influences on narratives of agency surrounding breast cancer risk. In contrast with the cynical notion that maybe nothing really matters anyway, the opportunity to "engage social suffering and to rethink policy, programs and moral initiatives" (Kleinman, 1997, p. 9) is a potentially transformative rejoinder to the "disordering effects of advanced capitalism which, like some universal solvent, appears to many to dissolve all that really matters" (Kleinman, 1997, p. 9).

By opening up space for critical self-reflection on our world and ourselves, we can prevent ourselves and others from becoming worse people under the pressure of changing conditions. We can protest and resist a dangerous moral ethos in our families, workplaces and communities...we are morally responsible for ensuring that others understand the social injustice our worlds routinely create, including what we have brought about by our own actions. And we are also responsible for doing something about injustice. (Kleinman, 2007, p. 24)

People's moral choices in the face of injustice, suffering, and danger are reflections of their values, of the local realities of their existence, decisions grounded in situatedness. The women in the study are self-reflective about the uncertainty of dangers around them and the human responses to suffering. They also talk about what really matters and what they work to retain. They describe a sense of responsibility about "doing something about injustice" through various strategies. As a form of agency, the women's narratives show that biography is a conscious and reflexive process of selecting events and issues in the construction of their risk strategies.

Sarah was contemplative about her priorities. "I don't know what we do with [knowledge of breast cancer risks]. I mean, sometimes you just put it out of your mind and not even think about it because what am I going to do? I've got to live my life." Living her life, of course, meant considering local employment and income prospects. "If you decide you just can't take it anymore and say, 'I'm going to leave'—where are you going to go? Especially in Windsor. So, it's just not that easy to say I don't want to work there anymore." For Susan, enjoyment in her job influences agency. "The truth is, at the end of the day, I still enjoy what I do. You have to like what you do, I think."

Lindsay looked at agency retrospectively, prioritizing health with knowledge of breast cancer risks at the Bridge. "Maybe I wouldn't have applied for that job on the posting website if I had known that [breast cancer risks were present]. Honestly, I probably wouldn't have. I don't want to put myself in an environment where exposure could happen." Lindsay then moved her gaze to the future. "I think it is definitely the younger generation that is going to take steps forward...I am super hopeful. I think [they] are going in the right direction." Sarah agreed a new generation of bridge workers had a role. "Pass the torch, and whoever is there, it's up to them to do the fight now." Mary Anne's moral imperative made her want to take action. "If I can contribute or help somebody who is trying to make a difference, sign me up. I'll help."

Jackie ascribes moral agency to her employer, viewing it as part of a broader health approach with collective responsibilities. She said, "I think there is a definite obligation to make sure that people are in a healthy and safe environment and not something that is just for the day or during your shift. It's an overall course of your career. If you are expecting to be at a location for twenty to thirty years, there should be an expectation that you want to manage your employees' health from all avenues for the duration of the time that they are under your care." In the absence of their employer assuming responsibility, the women contemplate moral decisions about action framed as a choice. Julie's thinking is grounded in her standpoint of awareness of risk and a moral choice but is nonetheless inconclusive. "It is hard to say. I would like to say, if it ultimately was my choice, it wouldn't be my choosing [to work at the Bridge]. Because if I could work somewhere, if my job wasn't at the busiest crossing in the country, maybe it would be different. Maybe the fumes and the concentrated air pollution wouldn't be such a factor, so it is hard to say." Julie began with individual agency and then returned to her standpoint, asserting a role for her employer as situated in a wider social context of moral priorities where external technical functions are recognized. "I think that my employer could probably do more for us as far as a cleaner environment. I think that they could. There is enough technology." Culture, structure and ideology are then incorporated into her narrative: "I think it becomes a financial thing. They just don't want to invest that money, you know, in a better filtration air system and things like that. I am sure there are the means to make it a healthier environment for us." Julie comes back to internal factors, where psychophysiological processes, coping, and individual choice re-emerge. "I mean, hey, it's my job. I don't really... I do have a choice where I could transfer somewhere else, but in the same respect, I kind of don't have a choice because I do have two kids to provide for, so it's just one of those, 'I have to suck it up and go to work' kind of things, you know, and hope that breast cancer doesn't have my number." Her moral experience of uncertainty seems unresolvable.

Like Julie, Erin speaks of individual bodies, choice, and moral priorities, problematizing them in the context of external factors. "It's our health, it's our bodies, and we should be able to make the choices. I think if you don't have the information, you can't make the choice. You can't choose to prevent [breast cancer] because you don't have the information." Samantha also problematizes the notion of individual choice—her words reflecting that from her standpoint, the choice may be imposed and, therefore, not an authentic choice at all. Samantha asks: "Did I make a choice? No, and yet, yes. I could quit. I hear that a lot. 'Well, if you don't like it, just quit,' you know as a way of shutting up complainers."

In the absence of a real choice to leave their jobs, the women's standpoint oriented them to future capacities. Lily's narrative combined the prospect of hope with her awareness of the past and present circumstances. "I know that with the new Gordie Howe Bridge, we actually have labour relations people dedicated just to be on that [health and safety] committee and to look at everything. Perhaps it is the sign of the times." Lily hopes that the federal government will address risk-bearing exposures. "We are in 2018. Things have changed. Obviously, a lot more people became sick. Maybe they are taking that into consideration." Julie's standpoint also landed on hope as she reflected on present and future agency capacities around breast cancer risk mitigation. "I do intend on being a lifer. This is a job I know I am going to retire from... so if there is something that is there and something that is going to affect me...I would hope that they would make the conditions to lessen those causes. I would hope they would do something about it."

#### **Conclusions: Transcending the Implication of Individual Volition**

At the end of our conversation, I asked Lily, whose breast cancer treatment was still front and centre: *What do you hope for? What do you think we need to see done here?* She answered:

That's a good question. Better compensation for those that are diagnosed. Definitely awareness. And now with the new Bridge being built, if [breast cancer] is caused by our environment, they have to be able to make revisions so that there is more protection, that there is better air ventilation, that there is better everything. I mean, it's a great job, but...it might be dangerous to your health. I

mean, God knows after thirty-one years— this is not where I wanted to end up.

Lily recognized that choices around risk mitigation were more significant than her individual volition. Larissa reflected beyond the individual to the capacity of the public to intervene as agents where personal choice was insufficient for risk reduction, serving wider societal and national strategies: "Our location is one of those locations that, in many respects, has a reputation. The ports around the nation know about Windsor, not always for good things. So, I am hoping that if these risk factors are being shown to be an issue here that we can be that catalyst that helps everyone nationwide."

Agency concerning strategies for breast cancer risk mitigation at the Bridge emerged in the women's narratives through various solutions: for example, changes in exposures and work practices; in the information reported by media, doctors, employers, and the health and safety committee; in training; in compensation; at the level of regulation and policy; in future practices including taking into account all of these factors at the future Gordie Howe Bridge. The changes discussed by the women seek resolution of the conflicts in health systems between biomedical and social realities through social and political change. The narratives illustrate the multiplicity of influences on agency's imaginings, with professional, folk, popular and experiential understandings of risk mitigation incorporated into their standpoints. The risk mitigation strategies outlined in the women's narratives expose the uncertainty inherent to the concept of risk. While they offer many suggestions for different ways in which they thought risks could be controlled, the women are still tentative in many ways. Though Susan, like many others, says, "nothing is in our control," she also believes there are sites and agents who can control risks.

This isn't the first time we have discussed breast cancer and the risks that we are exposed to at the Bridge, but it's almost like I need somebody to say, 'Okay, this is the risk, and this is the solution' and then have those two brought together. I think we all, in the back of our mind, know the risk is there, but I just don't think we have the means to implement a solution yet. I think there is that missing link in the middle.

That missing link is something considered by other interviewees as they try to put the pieces together into breast cancer control strategies, their deliberation of agency illustrating the systems they are operating in.

The narratives exemplify Emirbayer and Mirsche's (1998) definition of agency provided earlier. Agency is temporally embedded, socially engaged, and looks towards the future with the past's knowledge guiding the possibilities. The knowledge of how women understand and integrate information within their narratives of agency can facilitate action around environmental breast cancer risk mitigation. Adaptive tasks such as including better and new approaches to strategies for knowledge translation, knowledge mobilization, regulatory and policy modification and creation, risk mitigation at the individual and collective level, in setting priorities for future research investment and perhaps shifts in social and cultural values must be addressed. Distinct narrative typologies (Frank, 1995) are identifiable in breast cancer risk narratives for women at the Bridge. Narratives of agency contain the numerous strategies the women constructed in response to breast cancer risks, from personal to structural. More specifically, narratives of agency directed at breast cancer risk mitigation transcend the implication of individual volition to produce a range of multi-level, culturally-based strategies for action, reflective of a socioecological framework of health (Bronfenbrenner, 1977; Schettler, 2015). Based on the analysis, this narrative typology is *Transcending the Implication of Individual Volition*.

The process of narrative construction as socially and culturally contextualized and produced, while taking into account the complexities of breast cancer risk, is evident from the standpoint of women's understandings and knowledge. The analysis elucidates how complexities of risk understandings are contextualized through the development of strategies for risk mitigation. This phenomenon is especially evident as the women describe environmental risks for breast cancer, particularly those identified in their workplace at the Ambassador Bridge. The women transcend the implication that they are personally responsible for controlling their risks for breast cancer at work and elsewhere, pointing to environmental factors and the uncertainty created by the myriad risks for breast cancer outside of modifiable risks.

The women transcend the implication of individual volition, incorporating environmental risk knowledge from various information sectors, contemplating agency beyond the individual situated in the nested levels of a socioecological system. Transcendence is evident as they describe personal strategies while also incorporating workplace, health system and structural strategies. The strategies for breast cancer risk mitigation the women construct in their narratives are moral choices made in the face of injustice, suffering, and danger and are reflections of their values, their priorities grounded in their local realities. The women's narratives of agency reflect that:

Even in the absence of tragic events or disabling illness, people struggle steadily throughout their lives to hold on to those things that matter most to them, things such as status, jobs, money, family ties, sexual intimacy, sense of order and selfcontrol, health, life itself, and also religious commitments and political arrangements, and all sorts of culturally and personally specific agendas" (Kleinman, 2007, p. 6).

What matters to the women as social actors and as agents of change transcends individual volition to cultural, social, political, and spiritual considerations and a sense of responsibility for doing something about inequality through the strategies presented in their narratives.

Drawing from their standpoint, including their histories, experiences and situated issues, the women developed a broad scope of enacting agency, even while not naming it. Women conceptualize agency through temporal and spatial understandings of their constraints and their possibilities, their imagined futures, and the construction of different spaces for action and reveal their critiques and understanding of themselves and society. The narratives bring out a dynamic movement with various types and levels of agency, from focusing specifically on their individual lives to social and political awareness and responsibility to society more broadly. The narratives outlined and worked through processes that moved through finding meaning, constructing critiques, and taking overt and courageous action and activism. In their stories, the women spoke through an evolution from recognizing the seeming implausibility of change to imagining a different future where change is a defining characteristic of their agency. Agency in their narratives is manifested in explanations of risk and managing risk in ways that are meaningful to them grounded in their social location.

A significant aspect of agency that emerged in the narratives was the concept of power, often framed by conflict. At its core, agency is about power, present in all levels of a socioecological system. Power—and *powerlessness*—are addressed in the next chapter.

## **CHAPTER SEVEN**

# Tensions, Conflict, Power, Resistance: Exposing the Paradox of Breast Cancer Control

Women workers from the Ambassador Bridge in Windsor, Ontario, Canada produce critical insights in their narratives of breast cancer risk. Conspicuous elements of the women's standpoint emerge in an analysis of their narratives. Beyond the broad study themes—risk, environment and agency—which correspond with the study questions, the women's narratives point to the influence of their broader social location in a socioecological framework. The influences include economic, political, and structural aspects of the women's understandings of breast cancer risk mitigation, both as workers at the bridge and as members of a larger society. Tensions producing conflicts, power and points of resistance conspicuously emerge in the narratives. Contemplations, questions, and meanings materialize as resistance to culturally constructed meanings of breast cancer risk and related agency in the face of those risks—in the workplace and their larger socio-cultural contexts. Their words of resistance demonstrate the struggle between their experiential knowledge with other knowledge sets they draw on in breast cancer risk understandings.

In this chapter, elements of resistance to dominant cultural breast cancer risk discourses, representations, strategies, and values that emerge in the women's narratives are explored and analyzed. Their narratives of resistance are expressions of confidence in their experiences and standpoint knowledge and serve as counters to the prevailing messages on breast cancer risk. The resistance embodied in their words and action strategies challenge the ruling relations that reinforce existing risk frameworks and eclipse women's knowledge. They draw on their knowledge derived from multiple information sources, their community, social networks, and their personal and shared experiences as they demonstrate tensions and substantiate doubt, suspicions, and observed inconsistencies. Through this process, they produce social and political strategies for risk mitigation.

As the preceding chapters began to uncover, challenges to the hegemonic discourses are evident in the women's understandings of risk and narratives of agency. This chapter examines the perspectives and context of their resistance to the responsibilization of the individual for breast cancer. Among the paradoxes evident in identifying the narratives of resistance is that while the women describe a sense of powerlessness over breast cancer risk mitigation through their critique of personal responsibility, they cast themselves as agents of change. They see themselves in the context of unequal power relationships, and yet they resist this by envisioning their power to change these dynamics. Their stories illustrate, analyze and critique inequalities related to gender, social class, and power. In keeping with the conceptualization of resistance as described earlier, the very act of telling their stories and constructing their narratives is a form of resistance that challenges power and their oppression.

The women's narratives shed light on structural forces that contribute to breast cancer risk and aspects of the breast cancer experience that the dominant discourses omit or relegate to the margins (Porroche-Escudero, 2011). In doing so, their narratives challenge the dominant biomedical discourses of breast cancer. When scrutinized, the tensions they raise illuminate hegemonic structural, societal factors. However, as they narrate their experiences in the context of questions about breast cancer risk, it becomes evident that tensions are sites of struggle where resistance can change structurally rooted risks. These aspects, as brought out in the narratives, contribute to narrative analysis frames and offer an indispensable criticality to the problem of breast risk. Their narratives offer a contrast to "the canon of scholarship that has built up around illness narratives, scholarship that is most often descriptive and classificatory and infrequently critical in nature" (Nielsen, 2019, p. 42).

#### **Tensions and the Narratives of Resistance They Produce**

Multiple tensions are evident in the women's narratives. Tensions on their own do not fully explain the complexities of these women's struggles, but analyzing the tensions facilitates locating their subjective experience in their situated realities. Furthermore, they point to the unequal structural contexts where the women experience breast cancer risk and agency. The various tensions described in their narratives develop through words and discourses present as forms of resistance to dominant narratives of breast cancer risk and women's health more generally. The resistance constructed in their narratives highlights the interconnectedness of information sources and the nestedness of women in their socioecological relationships and structures. The development of narratives of resistance is not only emblematic of women's individual agency on breast cancer risk understandings and experiences but also challenge dominant social and cultural narratives.

Samantha's narrative brings out numerous tensions. A veteran of CBSA for over a decade, she had an educational background that gave her a language to speak analytically, seeing the problem of environmental risks for breast cancer and the inherent

structural conflicts in relation to her own social and cultural context. In this instance, she emotively addresses the tension of working for a living in an unhealthy environment.

It is sad, isn't it, when you talk about health? It is so close to the bone. It is life and death. It is difficult to think about your own death and think it might be because someone is not protecting you in your workplace. That's difficult to come to terms with. So, it is difficult, but that's the struggle that we are in.

The dissertation began with this quotation as emblematic of key understandings of the study. Samantha's biography intersects with her awareness of her social and cultural context, where multiple tensions are evident.

Biography is a site that reveals the contradictions and contexts of power structures and women's subjective negotiations with these (Collins, 1990; 2000). In other words, biography does not just bring out women's lives and experiences; it also identifies politics and structural oppression. Samantha's biography, as it emerges in her risk narrative, connects air pollution and shift work at the Bridge with breast cancer risk. Though Samantha was involved in workplace health and safety initiatives over many years, she believes her health is compromised in a way that she feels she has no control over. She describes a workplace of involuntary exposures<sup>10</sup> against a backdrop of avenues for agency over exposures. These are obvious tensions for her, conflicts she feels she is personally unable to resolve. Samantha illustrates the complexity and tensions of the interactions of the ecological system where agency is both possible and constrained.

<sup>&</sup>lt;sup>10</sup> "Cancers caused by involuntary exposures to environmental carcinogens are most likely to occur in subgroups of the population, such as workers in certain industries who may be exposed to carcinogens on the job" (https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/carcinogens).

The tensions Samantha and the other women describe become points of resistance, expressions of barriers and possibilities, portrayals of subjection and power. The narratives provide "personally and socially meaningful explanations" in the management of risk (Kleinman, 1978, p. 87) that are "attached to particular social relationships and institutional settings" (Kleinman, 1978, p. 85). Narratives of resistance developed from the women's standpoint cast them as agents of change in the socioecological conditions of their inequality related to biomedicine, money, gender, compliance, systems, and power. These conspicuous aspects of the narratives elucidate underrepresented possibilities for improved public health understandings, communications, and strategies for breast cancer risk mitigation at the Bridge and beyond.

## **Biomedicine**

Resistance to the dominant discourses of breast cancer risk is illustrated in feminist responses, especially those responses that resist coercive practices in biomedical frameworks that blame women through discourses of personal responsibility (Wilkinson, 2001, p. 273). The resistance to the standard biomedical narrative by the women at the bridge is a conspicuous aspect of the narratives in this study, illustrating the experience of health and illness is influenced by and negotiated among "socio-economic forces, and beliefs, values and practices" (Porroche-Escudero, 2011, p. 48). The women's narratives of resistance illuminate contradiction and reveal how women's experience as knowledge is frequently suppressed. Refusal or denial of women's experience is supplanted with narratives that validate their experience as knowledge, the emergence of experiential knowledge becoming more conspicuous as they denounce the dominating force of the biomedical discourse. Their narratives resist closure on biomedicine as the authoritative narrative on breast cancer risk, taking into account experience in their social and cultural structure.

Just as women's biographies accommodate and contend with tensions and contradictions, biomedicine produces particular tensions for the women. Biomedical frameworks impute agency to structural and political forces. Women draw from feminist discourses and their own life experiences to work through the contradictions. The most obvious of the tensions between biomedical and socio-cultural explanations are genetic risk factors eclipsing women's experiences. Dominant narratives reinforce the power of biomedical systems. Nonetheless, while many women began their risk narratives attributing breast cancer risk largely to genetic factors, their narratives developed, and they incorporated other factors understood, observed and experienced that contradicted or undermined the genetic explanation. Tensions in the confrontation of biomedicine with other cultural and experiential understandings are present when the women discuss and deliberate genetics and environmental risk, highlighting where the risks are outside women's control. The construction of resistance to the biomedical orientation is grounded in the contexts where women's knowledge is produced and understood.

The women's narratives that resist biomedicine include sharing their awareness of multiple breast cancer cases among their workforce. Bonnie said, "I knew of ten, but it could be twice that easy because you just don't see them [from other shifts]." The numbers recounted by the women are drawn from shared information, observations and experiences, and in some cases, institutional knowledge from formal documentation on peripheral issues that incorporated information related to a diagnosis or treatment for

breast cancer. One woman reported she knew of 30 women workers from the bridge who were diagnosed with breast cancer. The numbers of cases remain formally undocumented and are therefore not established as fact. The failure to formally document the cases contributes to uncertainty—perhaps the intentional manufacturing of uncertainty prevalent in occupational and environmental health disputes (Michaels & Monforton, 2005; Michaels, 2006). The numbers reported in the women's narratives are high when compared with incidence generally and regionally, given the size of the workforce, reported to be between 130-180, and 30-50% of them women<sup>11</sup>. A published paper reports 16 times higher breast cancer incidence at the Ambassador Bridge based on reports of eight to ten cases (Gilbertson & Brophy, 2018). Official confirmation of a breast cancer "cluster"<sup>12</sup> at the Ambassador Bridge is a continuing challenge (Gilbertson & Brophy, 2018; conversations with key informants, 2018) by those who claim its existence, including many in the workforce, the union, and compensation advocates involved in the case of the woman at the bridge. Despite the lack of official documentation, the women used their shared knowledge of cases to resist narrowly confined biomedical explanations.

Consistent with the understanding of socioecological influences and feminist standpoint, the women's experiences produce conflict with formal knowledge, becoming a catalyst to counter their oppression. Experience, when understood only as a personal and individual issue, limits the potential productive capacity. When women share stories

<sup>&</sup>lt;sup>11</sup> These numbers are estimates provided by key informants (noted in chapter three) in conversations before and during the course of interviews with the women.

<sup>&</sup>lt;sup>12</sup> "The US Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) define a cancer cluster as a greater-than-expected number of cancer cases that occurs within a group of people in a defined geographic area over a specific period of time" (https://www.cancer.org/cancer/cancer-causes/general-info/cancer-clusters.html).

and experiences, it contextualizes and grounds their social location as a valid source of knowledge. Information exchange through experience provides an avenue to confirm stories and see commonalities as systemically produced. Experience becomes a force for challenging dominant knowledge systems, including biomedical and ideological.

# **Suspicions**

In situating their experiences as resistance to biomedical narratives, the women raised uncertainties with regards to aspects of their understandings and struggled with suspicions about breast cancer risk that were difficult to formally verify—suspicions about workplace conditions and exposures; the volume of breast cancers among them; medical, professional, and workplace information sources; and the results of testing and investigations into workplace risks. The dominant breast cancer risk explanations were described in the narratives, and the individual and collective consciousness evolving from their naming their experiences and suspicions illustrate that standpoint is a critical knowledge site worthy of validation.

Julie, a CBSA employee for a decade and a half, described breast cancer risks from the standpoint of her experiences with her physician, the promotion of mammograms, conversations with co-workers, news, and women's magazines. She reports knowledge of multiple cases of breast cancer among her co-workers as well as the compensation case. Julie works to reconcile the conflict between professional and experiential knowledge of risks. "Genetics, but, yes, I do think environmentally. And not just regular air pollution. We are in a concentrated form of it." Though she pointed to workplace environmental exposures, she expressed uncertainty because of a lack of corroboration from professional information sources. "We don't realize how much we are really taking in. And that is the part that scares us." Julie and the other women experience a conflict between their knowledge and the employer's narrative that downplays and negates concerns about ill-health related to exposures at the Bridge. Efforts to verify the volume of exposures have failed. "We all have our suspicions, but you can't put your finger on it. And then when they come to do the air quality testing, it ends up being a breezy day."

Julie had given a lot of thought to trying to understand the particularities of the exposures, and her narrative incorporated how the standards and technical and scientific information, including legal limits for pollution, were used in explanations to the workers by CBSA, WSIB, and others to dismiss suspicions and concerns about breast cancer risk. She experienced a culture of denial. "It's not a normal work environment. It's not normal." Julie and others believe their exposures are inordinate, though they are a regular part of their work experiences. She describes what it is like when a truck is stopped. "There is a concentration [of diesel exhaust]. It hovers there. It is just a constant." Despite concerns and tensions between her experience and reports, Julie plans to be a "lifer" because of job benefits. Still, she suggests action should be taken. "I find that people, especially the government, instead of being proactive, it's reactive. It's unfortunate."

Lily, who worked for CBSA for over 30 years and was diagnosed with breast cancer, identifies a tension related to information from the professional sector, specifically the dominance of the biomedical perspective, and suspicions from experience with an awareness of the number of cases among women workers at the bridge. Lily asks, "Can we say to them [new employees] there is a chance [you will get breast cancer]? That we don't have anything other than our suspicions guiding us right now? Would it be part of our health and safety presentation to them? But even then, what do we tell them?" The act of information sharing was imagined as a form of resistance to address the tension, showing the confidence in the knowledge garnered from experience.

Participating in interviews for this study was an act of resistance to the expectation for silence by CBSA workers about their work conditions. By breaking the silence, the women resist the master narrative that fails to acknowledge breast cancer as work-related. This form of agency appears in Audre Lorde's writings to "break silence, to do social justice work differently, to enact self-care not only when facing cancer but also in the everyday inhospitable environments many women face" (Nielsen 2019, p. 144). Women's standpoint that names their experiences produces resistance through the creation of narratives that imagine social justice achieved in part through validating women's knowledge and becoming "narratives of repair" (Nielsen, 2019, p. 138). Repair resists the powerlessness intrinsic to the muting of risk concerns raised in women's suppicions about environmental risks for breast cancer.

## **Economics**

The juxtaposition of the economy and individual financial security with health is another tension that emerges in the women's narratives. The women's stories bring out how neoliberal corporate discourse is conspicuous and dominant, not only because of the interests of capital but as lived realities of the need for money for survival. Women are interpellated to act as good neoliberal workers who establish financial security. The critical role of finance makes economic narratives harder to undermine. The tensions surrounding economic questions, as expressed from the women's standpoint, draw out structural and social determinants of health. The World Health Organization defines the social determinants of health as:

the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries. (WHO, 2019)

Social determinants of health fill spaces between the dichotomous distinction of lifestyle and environmental factors related to breast cancer. By incorporating tensions and conflicts of income, finance and economics into their narratives, the women highlight another site of their resistance to the dichotomy. The phenomenon as expressed by the women is alluded to here:

The distinction between lifestyle and environmental factors is becoming increasingly blurred as researchers turn their attention to the social and environmental determinants of health-related behaviours...The "upstream" social determinants of disease and health are the neighbourhood conditions, environmental exposures, social and occupational opportunities, and personal resources that create the context within which health decisions are made, and health behaviours are carried out. (White et al., 2013, p. 6)

In their resistance to the dichotomy, the women invoke the need to interrogate the relationship between environments and breast cancer and to recognize social determinants of health in their search for knowledge that is representative of their standpoint. This act of resistance to personal responsibility finds them grounding their

narratives in a socioecological framework where cultural, social, political, governance, and economic influences interact. Social determinants of health, as raised by the women, included pointing to the conditions in their lives they do not necessarily accept or endorse. Their standpoints exemplify tensions between health protection and social values that prioritize the movement of capital above all else.

Shannon ultimately left her job with CBSA after the experience of an otherwise healthy family member dying of breast cancer. She said, "They look at everything with dollar signs. Is there anything done about those carcinogens that are crossing through here?" Shannon describes how she reconciled the tension of different priorities from the institutional and workplace culture. "I started kind of thinking to myself, 'If my environment is [having] an effect on my health directly and if I know it is, how am I going to continue working in a place when I know what it is going to do to me?" Resistance for her was leaving the job. She recognized the difficulty of choices women make in their lives and the tensions that become apparent when weighing financial security, career benefits, and health in the context of an economy which devalues health and family while prioritizing economic efficiency.

Shannon sees how her marriage influenced her choice to leave the bridge. Having a spouse with job security, a good wage, and benefits gave her financial privilege, in contrast with co-workers who lacked such means. Socio-economic class is a tension that Shannon and others place in their narratives, highlighting the "systemic relationships between the components" (Kleinman, 1978, p. 86). The experience of breast cancer is marked by a "devastating combination of factors," including classism, politics, culture, and economy (Porroche-Escudero, 2011, 96). Social determinants, as captured in the socioecological model (Bronfenbrenner, 1977), underscore the nested relationships, conditions and structures that influence women's health decisions (Schettler, 2015), such as those made by Shannon and others.

Kathy had 17 years at CBSA before she left the job and said, "You couldn't pay me enough money to go back there now. Not just for the job, but just being so much more aware of the health issues and everything else." Though unequivocal now, the absence of other well-compensated job opportunities for women was a conspicuous tension.

I think just about everybody in my age group that worked there all had education. But the money is good. And you can't turn down that money. Money kind of trumps everything. You forget about everything else. And I think as you get older, then you realize that is not the important thing.

Erin, still early career and looking at her future, discussed financial considerations: "I think people are very concerned about their financial security, and that often is the priority. You can't live without money, so I think that is where it comes from first." Lily also sees finances in the long-term: "It's a job, and I do it to make money, and I take care of my family and myself later in the future." Erica contrasted working for CBSA with low-paying job options: "The way I started as a student, it was just a student job, just like a job at Burger King or something...you realize its decent money and secure, so you stick around." The financial compensation and stability compared with other women in the region are a tension with concerns about exposure to breast cancer risks at the Bridge.

Larissa resists the idea that money should be the dominant focus: "Everything, at the end of the day, it all comes down to money. We have to change that." The standpoint of the women on the structural influences on their breast cancer risks emerge as questions of agency about values and inequities built into socio-cultural systems. Structural determinants and social inequalities are embodied experiences (Porroche-Escudero, 2011, p. 110) that they relate in their breast cancer risk narratives. "Working to prevent breast cancer through lifestyle choices ignores the hard fact that we don't all share equal access to the same "lifestyle choices...we lose sight of the social justice issues that limits access" (Breast Cancer Action, 2019).

#### Gender

Many of the women's narratives point to inequalities related to gender and the perception that women's health is unimportant in the context of the culture at the Bridge. Furthermore, they feel protecting their health in the context of these inequalities is outside of their control, creating another tension and a point of resistance to the master narratives of women's personal responsibility for breast cancer risk. Gender-based inequalities are sometimes difficult to identify because of taken for granted practices in institutional and organizational frameworks. Feminist and social justice frameworks facilitate identifying these phenomena within patriarchal structures, allowing the production of critiques from women's standpoint. Women's experiential knowledge, as described in their narratives, illustrates how gender shapes women's experiences, exposing how structures are shaped by patriarchy and behaviours are governed through gendered ideological concepts.

Gender inequality was introduced as a site of power difference that underscored the recognition of how socioecological circumstances can influence and constrain individual agency on breast cancer risk. Bonnie saw how gender inequality, as reflected in income disparities and even marital status, influenced individual women's choices related to breast cancer risk. "I was lucky. I had a husband who was making good money, and I could take a pay cut. But there are a lot of single moms out there that worked [at the Bridge], and there was a lot of people that couldn't [leave their job]". Judy said: "It's not fair to be a woman. They need to listen to us better." She inferred that voice was a site of disparate power, where men's perspectives are heard and women are disregarded. Shannon recognizes that there have been shifts in gender disparities at the Bridge in representation in the workforce. However, it has not resulted in equitable treatment of health concerns.

That's the part that upsets me. It's becoming more and more a 50/50 female to male workplace. All these women are getting this disease and not many men. It's frustrating because it doesn't really seem like there is anything to be done about it. As much as our society right now is moving towards equal pay and men finally paying for the things, it's still predominantly run by men. So, I guess I wonder if that has something to do with it, too, because it's not that important to the [men at the Bridge].

Samantha speaks about the gendered disparities in addressing health concerns as a question of culture and values.

What do we value? Do we value women's health, and how much? Because everyone would be very eager to say yes, but how much do we value their health? And I think that that's where you would find that the trade needs and pushing those trucks, pushing those cars—as we call it at work—is going to end up feeling more important to decision-makers or the power players than protecting an individual woman from a risk. Conflicts in values through the lens of gender inequality and economic power are both articulated in Samantha's standpoint.

Kimberly's narrative demonstrates her education in family and gender studies through feminist explanations factored into her understandings of breast cancer risk and agency. She knew of multiple women at the bridge with breast cancer and believed gendered attitudes impact whether and how environmental risks for breast cancer would be addressed. Kimberly sees breast cancer risk mitigation as beyond their personal control, arguing governments have responsibility. From her standpoint of 20 years working for CBSA, she describes the workplace cultural attitudes on gender. "There are just some things that are still just male views." She applies a historical lens:

The roots were all male. Originally there were no females that were in that job years and years ago. You are beginning to get the shift of mindset where it's not just men here now. And the breast cancer thing, I don't know if it's as prominent. It's just that's the environment that we have come from, and it's not as important [to the men].

The tension of breast cancer as a predominantly female disease, located as a women's issue within gendered ideologies and practices that undervalue women in a culture where male values dominate, exemplifies the problem of health-related aspects of societies as cultural systems that "organize particular subsystems of socially legitimated beliefs, expectations, roles, relationships, transaction settings and the like" (Kleinman, 1978, p. 87). These components of culture that reflect oppressive power systems are also reflected in mainstream breast cancer culture and the medical system where gendered attitudes articulate the breast cancer experience in terms of women's bodies as weak and

vulnerable (Ehrenreich, 2001). The women's narratives of resistance are presented as a tool "needed to repair damage enacted through oppressive power systems" (Nielsen, 2019, p.45).

Annie describes the normative origin and perpetuation of male-dominated culture at the Bridge.

Frankly, it was very sexist and a lot of the people who became supervisors and then managers and then moved on to wherever, they were almost all male. I found it very sexist. It was just a very toxic atmosphere, and [women's] health was not even thought about. And actually, I think being a woman, I felt under a lot of pressure to not complain about health situations that I perceived because that was, you know, you are being wimpy or whatever, you are not doing your job.

Judy's standpoint of the gendered tensions is expressed through a vision of social resistance:

We need to advocate for ourselves loud and clear. But that doesn't necessarily mean that our society is going to listen to what we have to say. Because we are still living in a world run by men. Women try to make a difference or try to make a move, and they just get stomped on, most of the time.

The refrain of gender inequality expressed in the narratives is grounded in socioecological context across multiple levels of the system. The women's standpoint suggests gendered inequality manifests not only as contributing to their risk-bearing environment, but it also produces tensions and sites of resistance. The gendered inequality in their workplace and broader socio-cultural contexts are spaces where the women envision change is necessary to address gendered health inequalities, including risks for breast cancer at work and beyond.

# Harmony and Compliance

The women identified the concepts of harmony and compliance in many of their narratives, which is illustrative of another source of tension for women at the bridge. Noteworthy is that harmony and compliance are also gendered: passivity and politeness are expected of women. These social influences present a challenge to women, as they work to find and assert their voices and establish that their experience reveals alternatives to dominant knowledge sets. The existence of these phenomena is evident in stifled attempts by the women at the Bridge to address their concerns about breast cancer risks. The knowledge produced by their "lay epidemiology"<sup>13</sup> divulges a cluster of breast cancer cases, yet institutional governance, health, and compensation narratives that deny the cluster reinforce the need to 'not rock the boat,' and advocate women simply accept the contradictory forms of evidence and continue doing their jobs.

Mary Anne, with ten years' CBSA experience, talked about risks related to shift work, the volume of trucks, exposures from the trucks and their contents. She told me when she heard about my study, her first thought was "finally," as for so long, she felt they had to keep silent on the issue. She also told me that her health concerns about the work conditions played a major role in her decision to leave the Bridge, just as it had for other women. Mary Anne and others explain that when breast cancer and working

<sup>&</sup>lt;sup>13</sup> "Two distinct elements seem to make up lay epidemiology. The first is empirical: lay beliefs about the causes, course and management of illness. The second is values: lay beliefs about the place of health and risks to health in a good life. In almost all the articles, lay epidemiology is seen as oppositional to public health in one or both of these elements" (Allmark and Tod, 2006).

conditions are raised, it often results in being ignored, concerns being rebuffed, negative reactions from management, duties being revoked, even firings. They learn that harmony is achieved by compliance. Kathy describes it like this:

They don't like people making waves, and if you make waves, they will find reasons to get rid of you. It's not as easy now without the money, but when we had the tolls, it was very easy to get rid of somebody you didn't like working there. You know, half their money could disappear, and you were responsible for that money, and now it's gone. So there were ways. It's probably a little more difficult now. But they eventually would find ways to get rid of you. They don't like anybody that is causing trouble for them there, making noise about anything and people I think were aware of that.

Lorraine reinforces what Mary Anne said. "Some [women] tried, some approached management, some got lash back from management. It's touchy. Or they just were ignored." Silence bred compliance.

Sophia Belle told me what happened after her breast cancer diagnosis: "I requested a change of venue from my work, which was met with a lot of resistance from management. I was told: 'well, if we do that for you, other people will try to get out of shift work.' And I said: 'well, I don't think anybody is going to try to get cancer just to get off shift work'". The implication was women should not ask for accommodations for breast cancer. Larissa's story adds to how women learn to comply to maintain harmony in the workplace. "I have personal experiences with not being supported by the senior management and my employer so, I guess that is what makes me jaded and not hopeful, not expecting that all that much will change." Bonnie's mindset as she retired speaks to the expectation for harmony as part of workplace culture. "When I was there, we had the power, that they weren't coming down on us real hard. But then they started to at the end...Just talking to you is making my stomach turn because I couldn't do it anymore. It was too frustrating." Bonnie's understanding of the pressure to comply is an embodied experience.

The practices and ruling relations at the Bridge served to stifle women's desire to enact agency for change, shaping their attitudes towards maintaining harmony and complying with the points of view of those with more relative power in the context of the workplace. Resistance is costly to the women at the bridge. The experiences the women shared illustrate that attempts to reconcile health concerns and risk of exposure are met with reprisals in various forms. The interactions between them and their managers reinforce a workplace culture where resistance to the "way things are" is not accepted nor tolerated. They experienced negative repercussions that taught them harmony and compliance are expected and maintained at the Ambassador Bridge.

#### System Interactions

External acknowledgment of breast cancers at the bridge was viewed as a possibility for resolving the conflicts faced by the women and as a means to facilitate the recognition of workplace environmental risk factors for breast cancer. The possibility of external supports emerges as another source of tension. The women at the bridge worry they are invisible to the public. Mary Anne asked, "Has anybody ever clued in about us women that worked there? And what about the young women that are working there now?" Dana told me, "One of our biggest challenges is changing the way we are viewed in the local community, and we have really started working on that in the last couple of

years." From public rallies to media messaging, the women and their male colleagues worked on their public image. Their narratives establish the health and risk connections between the workplace and the community where the workplace is located.

Lorraine turned the tensions of cultural and systemic roles and relationships into a strategy for resistance, saying: "I know we are not all scientists; we are not doctors, we don't know these things. But I think that is something the union would be able to work with, if there was someone working with them to make a plan, somehow change it [the exposures], or somehow help." She situates herself as an agent rather than a passive victim of her experience and connects her community and other systems. Nielson (2019) defines these narratives that challenge established roles and expectations as feminist counter-narratives, disruptive narratives, and narratives of resistance (p. 44).

A problem with trust was a complication and tension borne of conflicts between information sources and of the workplace culture for the women at the bridge. Lily refers to an occasion when following a request from the health and safety committee, testing occurred to evaluate the air quality and her standpoint and experiential knowledge led her to question the results. "I have to wonder when did they take the study? On a Sunday when there were no trucks?" She connects her doubt with knowledge of breast cancer cases, referring to a conversation with another CBSA employee:

She was telling me that they were counting, and in a matter of 3 years, there were 18 women diagnosed. In 3 years! When she told me that my eyes just—18! I said, 'I knew it was a lot, but 18?' And she said: 'yes, in a matter of 3 years there were 18.' And she was saying that they had called for an environmental assessment, and they deemed that everything was fine. And I said, 'really? They did an environmental assessment?'

Lily was skeptical of the validity of the results given what she and her co-workers experienced. The information coming from the different sectors of the system stood in contrast with one another, resulting in women's distrust of administrative and regulatory systems.

Erica sought resolution of the trust problem by looking through a future lens: I think it [the Gordie Howe International Bridge] will be cleaner. I think for your health it will be a lot better because it is not going to be privately owned. I would have more trust. I would believe that report [on air quality] more than what I see right now because anything that comes back when we complain about something, everything comes back, [saying] air quality is top-notch. I don't believe it at all. You are looking at where you work. You see it firsthand.

The tension between Erica's standpoint and incorporating her experiential knowledge against formal air quality reports and private financial interests collide to create a conflict that produces mistrust. The interactions of the multiple systems factor into Erica's assessment of present and future risk, and she envisions trust may be produced under different workplace structural conditions.

Susan's narrative illustrates that breast cancer risk and the related tensions at the bridge were pushed aside as a coping strategy. "I think it [risk for breast cancer] is an important issue. I think it is an issue that we have kind of pushed to the side for a little while, and I think this [study] was kind of the kick that maybe we needed to bring it back to the forefront." Past failed attempts to confront breast cancer risks at the Bridge served as a form of suppression of action by the women. The women revealed the *Windsor Star* article on study recruitment was shared among the women and on social media, and it had reignited the discussions between them. These discussions were a catalyst for reimagining their agency with the hope of recognition of exogenous risks, documentation of the cases, workers' compensation for breast cancer and mitigation efforts of future exposure to breast cancer risks. The role of information and the sources of information as part of systems that shape women's responses to breast cancer risk is illuminated in this example.

A socioecological lens grounds Mary's standpoint as she contemplates the future workplace, and she does not seem to have great expectations for improvements.

I think at the other bridge, the area that they are looking at building it, it's right in that industrial area. At least here there are trees - there is nothing there. It is 100% industrial, and it's right by Rouge River, that disgusting plant there in Michigan. That's where it connects to. I mean, so this is bad, but if you look at where that new Bridge is going to be, if there is a correlation [between environmental exposures and breast cancer] with this one, then I can't even imagine. I mean, that location is so much worse. But they didn't look at those factors, right? They looked at what was more convenient in terms of connecting a highway to a bridge.

The tensions in Mary's narrative reveal her awareness of structural and ecological influences on breast cancer risk. Policy, planning and governance surrounding the future bridge conflict with her standpoint on the factors necessary to reduce risks for breast cancer in her job. Mary's description of tensions in priorities alludes to how power

manifests in practices and where conflicts are produced through power disparities and disparities in values through the systems.

The women's experiences inform their challenge to the conflicts between the different levels of the systems and the cultural priorities and relationships inherent to the socioecological framework. From the women's standpoint, and interpretations borne of their situatedness as workers in their community, some tensions need reconciling in the "systemic relationships between the components" (Kleinman, 1978, p. 86). Though the women express resistance to the form and content of present systemic interactions related to their risk for breast cancer, they envision improved systems where trust is integral and where disparities in power and values are resolved.

For some women, the systemic tensions were experienced as constraints to their agency, and they gave up expecting change at work, stopped thinking about risk, or placed responsibility with others for dealing with the issue. Still, most imagined strategies for resistance, whether individually, collectively, in the workplace, or across other levels of the socioecological system. The variation in standpoints on tensions of breast cancer risk mitigation in their environments illustrates interactions among and across levels of the socioecological model and their influence on health.

#### Difference and Power

Women's lives and experiences are often distinctly different from dominant ideas and representations. The difference is frequently revealed in what is missing in dominant discourses and the experience of powerlessness. Difference is sometimes experienced as marginalization from normalized ideas and practices around gender, racialization, class, and more. Difference and power are distinct but deeply connected in the practical realities of socio-cultural practices and relationships. Power manifests itself in interactions, and women recognize power and oppression in affective ways, including discomfort, insecurity, and alienation. Women also recognize powerlessness in societal values that stand in contrast to their own and produce a collective identity that distinguishes them from more powerful agents. This value conflict is true in the experience of breast cancer risk and the experience of health systems generally, as revealed in the narratives of the women at the bridge.

Identification by women of the influences on difference and power in breast cancer risk experience produces efforts to resolve conflicts in the system between biomedical and other narratives through social and political change. Differences in health systems can "predict conflicts in health transactions" as well as demonstrate "historical, political, economic, technological and epidemiological influences on health care" (Kleinman, 1978, p. 91). The women at the bridge are attuned to the influence of power differences and the conflicts produced through different cultural, systemic and structural narratives as represented in the socioecological levels. Narratives of resistance constructed from the women's standpoint exemplify "the impact of underlying power dynamics and normative gender constructions on women in relation to illness and narrative" (Nielsen, 2019, p. 44). Identifying sites of power and unequal power "relates sociopolitical and environmental determinants" (Kleinman, 1978, p. 89) and facilitates resolving conflicts in the system towards adopting more effective health care strategies. Their narratives illuminate the "ways that structures of power such as class, age, gender, and disability, intersect and 'conspire' through a web of social beliefs, practices, norms

and expectations to shape, and exacerbate, women's experiences of illness" (Porroche-Escudero, 2011, p. 3).

When the women spoke about control over breast cancer risks, the narratives conveyed their sense of powerlessness, barriers to enacting agency, and disproportionate power in the workplace and society. They see their power as disparate from management, the Ambassador Bridge Company, the Federal government, ideological and cultural forces, their union at times, and the wider public with whom they interact. Larissa's narrative negotiates powerlessness through its affective impact.

You have people who have been there a very long time, and they have been jaded, and they were very negative. But at first, it wasn't a big deal because I didn't have those experiences. But I have now since had those experiences with my employer. So, yes, I kind of have become jaded as well. I mean, I still care, and I still want to help people.

Larissa's conflict lies between the generation of her powerlessness but still identifying the presence of her agency. Sophia Belle captures how a false sense of power over breast cancer risks was created by management, downplaying the risks of the job. "We were bulletproof, and we were led to believe that there wasn't anything to worry about." She alludes to abuse of power by her superiors, implying they used their power to mislead the women by withholding information and suggesting the risk of breast cancer was not a concern.

Dana talks about power as a systemic conflict between workers, government, and private ownership:

[Air quality studies] are usually fought with a little bit of resistance from management and the Bridge Company. But we have had it done. And then the reports come back showing the air quality is safe. But I think in the back of our minds, not one of us is 100% reliant on that, right. You could tell us that, but we are out there for 4, 5 or 6 hours a day breathing in those fumes with the trucks right next to us.

Dana refers to multiple conflicts across various levels of power while also expressing how experiential knowledge is subordinate to administrative power.

Kathy's words reveal that powerlessness is not just individual and personally experienced, but also a problem understood as situated socially and societally. Again, abuse of power is suggested:

I don't want to accuse any government agencies of taking payouts from them, but there has been a lot overlooked over the years. Even times when we have called in the ministry to come check stuff out, they will show up and say this, and this and this needs to be done, we will be back in 6 months to make sure it's been done, and nobody comes back. There has been a lot swept under the carpet.

Kathy's standpoint demonstrates her experience of workers' lack of power in contrast to with Ministry officials whose power allowed them to ignore, deny and deflect concerns of breast cancer risk, using their institutional roles to do so. Shannon claims the CBSA also uses its power to effectively ignore worker's concerns saying they "would rather waste money on other things instead of taking care of their people. It's really funny working for CBSA because you really did get a sense that you are a number. You are a badge number, and you are just a number. You are easily replaceable." The sense of invisibility, existential alienation, and powerlessness the women feel compared with the power they perceive as situated in political, institutional, and governance structures are evident in the narratives. The experience of disempowerment by women workers is pervasive and systemic (Perez, 2019).

Samantha's narrative identifies another systemic factor, as she resists the power of corporate influences on governments by positioning power with citizens. "The interest of private sectors with government regulations and corruption then ends up creating the role of community to try to hold those government agencies responsible." Sarah's standpoint also ascribes power to citizens as a form of resistance to government power and inaction on breast cancer risk:

Somebody has to start it because the government is not going to start it on their own. They're not going to say, 'Oh, yeah, we're going to do this because we're nice.' It needs to start from people, a movement. It has to be people, grassroots, people banding together and pushing governments and politicians because you have to get awareness on the issue and the problem. You have to get it up there to the highest level.

Sarah's conception recognizes government power, paired with recognizing that collective citizen power can resist, challenge, and shift power dynamics.

Economic power was another site where women's resistance was expressed. Erica's standpoint exposes how economic considerations as a societal value have power and create conflict for breast cancer risk mitigation.

I don't think they will ever limit how many [vehicles] can come through. I think they would address more trees, better filtration. I think that stuff will be done. I would put a lot of money down to say they would never limit the amount of traffic that comes through. To me, it's a silly idea because it will never ever happen because of money.

Erica and other women experience the values attached to their health being ignored and suppressed and perceive this as a barrier to their resistance to dominant values. Larissa asks:

How many women have to get breast cancer that they can attribute it to the work where it changes? Where they don't let you be exposed for 12 hours a day? There are a lot of courses of action that can be done. Obviously, none of it would be in their [CBSA] best interest because it's not moving trucks across the Bridge, it's not moving cars across the Bridge, and that is their focus. Moving those trucks. Your safety, my safety, you being Canadian, my safety as an officer, my safety, my health all takes a back seat to moving those trucks.

The dominant cultural values, as understood from Larissa's standpoint, include a foregrounding of economics, efficiency, security, national interests. Women perceive their health as not valued at all or valued very little in contrast with dominant cultural and ideological interests.

Samantha's standpoint elucidates how the economic and political frameworks interact to influence Bridge operations. "Because of the power of the lobby of the truck traffic, we get torn in two directions on this. Because our city is built on the auto industry, and so is Detroit, and so that industry relies on something called just-in-time supply. This is the industry that defines our area." The implications of the industry and trade arrangements are complicated as Samantha explains. "So, when you talk about limiting environmental pollution, you are talking about limiting the trucks that deliver the different types of parts, which then limits the jobs of those workers who need those parts to build those vehicles, and it's an insecure industry.

Samantha continues, her imaginings for agency at a structural level emerging: "I'm not an entrepreneur, but can we not redefine these businesses in a less harmful way? But when we talk about reducing the harmful effect of traffic, what you are really talking about is redefining the whole trade relationship with every other country in the world that we have now at this point become really enmeshed with." As Samantha points out, there is no easy solution. "It's a tricky question, and I think it feels very much out of our hands, which is another reason why I think it becomes very easy to shelve it because the question is too big, and you feel too powerless because there is very little I think that you can do..." She continues recognizing that broader, systemic foundations contribute to the challenge for change: "...unless you are talking about really getting rid of our dependence on fossil fuel."

Though Samantha identifies potential strategies to mitigate risk, her standpoint represents the pervasive conflict of power difference and multiple points of resistance.

Larissa's narrative elaborates on these points, illustrating how privilege and oppression become expressed as priorities and values within a socioecological context.

When it comes to the risk factors for cancer, breast cancer specifically, it would involve not processing millions of trucks all the time. There are things you can do for each individual person. They don't have to be exposed for long times, those kinds of things. But as a whole, unless we are going to stop commerce, how are we going to do that? She went on to say, "It's all about money. So, they are not going to care more about my health than moving the trucks. They are not. They have made that clear on more than one occasion." Multiple tensions are evident in Larissa's standpoint as elucidated in her explanation, where she understands that money not only has value as currency but has a social value greater than concerns about women's breast cancer risk.

Power and conflict, value differences and tensions, were portrayed as incommensurable in the narratives. Despite the barriers identified, resistance was evident as the women maintained hope for change. They see the openings for agency and opportunities to resolve the conflicts in the system that put them at risk for breast cancer in their environments. They name potential changes and recognize the sectors and relational transactions within the socioecological framework where agency could be targeted. Julie said, "As much as sometimes anything with the government kind of moves at a snail's pace, you just hope." Larissa's mirrored Julie's hope. "Hopefully, the next place is a step in the right direction as far as taking care of the people who work there and the people who use the Bridge. I would hope that they would make the conditions to maybe lessen those causes [of breast cancer]. I would hope they would do something about it."

The women's narratives grapple with power and difference and the inherent tensions of structural inequalities in an ideological context that values economies and individualism over all else. Their words provide "personally and socially meaningful explanations" in the management of risk (Kleinman, 29178, p. 87). In the production of their narratives from their standpoint, the women envisioned themselves part of "a process and agent of meaning-making in the context of unequal power relationships between the person and the world surrounding that person" (Porroche-Escudero, 2011, p. 19). Power is central in the narratives, and they contemplate agency and seek to resolve conflicts between biomedical and social realities through social and political change, and efficacy in health care, through "resolution of psychosocial tensions and the evolution of adaptive cultural strategies" (Kleinman, 1978, p. 91).

The women experience tensions around information sources and issues of trust with professional, medical, scientific, and institutional domains as inequalities. From a feminist standpoint, the ruling relations as they impact the women are tensions whose resolutions are complex and rooted in the structures, interrelationships, and social determinants of the socioecological framework. Their risk stories are emblematic of the complexities of the contexts where they are rooted; their understandings produce strategies that apprehend the role of power and difference through resistance and spaces of hope.

#### **Conclusions: Exposing the Paradox of Cancer Control**

As we approached the end of our three and a half-hour interview, I asked Samantha, a CBSA officer of well over a decade, if she had any final thoughts. She replied, "I knew it was going to be in some ways difficult to talk about because of how painful breast cancer is, and I have kind of been near it. How painful it is to even think about it and think about the risks."

Samantha's narrative illustrates the intersection of her personal biography with illness and risk understandings as socio-cultural experiences, mediated by both internal and external factors. Samantha's and the other women's narratives are products of power, forms of resistance, speaking to "suffering where structural oppression is involved and where institutions, such as biomedicine, lay claim to legitimacy, authority and objectivity" (Nielsen, 2019, p. 16). The women lay claim to their power through the expression of their standpoint.

Health inequalities and social determinants of health, including social, cultural, occupational and environmental conditions that influence health behaviours and "choices," are illustrated and revealed in nuanced ways in the women's construction of their narratives of breast cancer risk. Dimensions of inequality and socially rooted health factors are presented as tensions, as narratives of resistance, adding to the question of control and the plausibility of agency around breast cancer risks. The women's insights, from their standpoint, illustrate that the question of breast cancer risk control is not a straightforward matter of choices or changes but is bound up in the complexities of social and cultural constructions and conflicts of gender, class and more. The phenomenon of their conflict is understood through the broader social, political, economic, and ideological contexts within which the narratives are being constructed and importantly through the theoretical lens of Kleinman's approach, feminist standpoint, and situated in the socioecological framework of the nested relationships of the individual within systems.

Tensions are placed and described in the women's narratives in various ways. Fear of breast cancer is moderated with expectations of a pension. Conflict exists between women's' knowledge of breast cancer risks and the number of cases in the workforce, and the lack of attention from physicians regarding their working conditions. A diagnosis of breast cancer with no genetic history and the suspicion of being workrelated is kept quiet for fear of negative repercussions at work. The narratives contain

216

explanations that counter and resist dominant breast cancer information and discourses, including media, mainstream science and medicine, and employers. Women's standpoint in their narratives reveals intersections of gender, class, and social networks in their experiences and understandings of breast cancer. The stories demonstrate conflicts between biomedical knowledge and popular knowledge as synthesized in their experience. The multiple conflicts and tensions evident in the narratives add to health knowledge, serving as tools that reveal the phenomenon that biomedical and epidemiological evidence cannot reveal (Porroche-Escudero, 2012). Through the lens of the women's lay knowledge, nuanced explanations of environmental risk factors and power inequalities are produced (Popay et al., 1998), facilitating a theoretical understanding of health inequalities related to breast cancer risk.

Power inequalities, as described in the narratives, point to and illuminate the socioecological structure and social determinants of health. The tensions within the narratives highlight alternative points of view and, as such, are sites of resistance. The narratives of resistance offer novel elements to the health system continuum, from identifying the risk experience, constructing of the risk narrative, locating experience in its wider context, revealing sites of tensions and resistance, to strategizing or enacting agency on breast cancer risk. The paradoxes the women captured in their stories lead to the development of the narrative typology (Frank 1995), *Exposing the Paradox of Breast Cancer Control*.

The women transcend the boundaries of the dominant breast cancer risk discourse of individual control over cancer to describe exposures emanating from the environment. The strategies for control over these risks, as seen through their narratives, reveal the

paradox of cancer control especially related to exposure to risks for breast cancer that are involuntary exposures, beyond the control of individual women. The concept of cancer control is typically that of a continuum, moving from detection to diagnosis to treatment; it assumes that control is possible with the implication that individuals govern their risks. As White et al. (2013) point out, expanding that continuum to include prevention renders the continuum irrelevant and invalidates the other aspects of the continuum—in other words, if there is prevention, cancer does not develop, and therefore there is nothing to screen or treat. When women are responsibilized for controlling their breast cancer risks on the premise their actions will prevent cancer, while at the same time involuntary exposures in environments are present, a fallacy appears. Women cannot control what is beyond their control. If involuntary or personally unmodifiable risks for breast cancer were addressed by policy, legislation, regulation, and practices, breast cancers associated with environmental and occupational exposures would be prevented. This would then render the continuum of control from detection to treatment irrelevant. Prevention of exogenous exposures further emphasizes the flaws of the continuum and the emergence of the cancer control paradox because, as long as women are powerless to prevent some exposures, they continue to need detection and treatment for breast cancer.

The paradox of breast cancer control as women's personal responsibility is evident when power and conflict are identified as contributors to risk in women's narratives. The tensions and resistance that emerge in discussions of power and conflict uncover a lack of individual control over breast cancer risk and relative powerlessness against involuntary, exogenous exposures. In bringing out the paradox, the women's narratives locate barriers to their ability to exercise control over risks for breast cancer across their socioecological locations. The concepts identified in the narratives, including biomedicine, suspicions, economics, gender, harmony and compliance, difference, and power, further illustrate the complications of controlling breast cancer risk. The analysis of the narratives illustrates that the women's risk understandings are located in a system of interrelated parts, where the individual is just one of the many levels of interaction and relationships in the socioecological framework.

The women's narratives characterize the functions and manifestations of power and the intricate ways women understand and harness power, individually and collectively. The knowledge produced in the analysis of narratives extends understandings about agency through the lens of women's constructions of their experience and the acceptance of knowledge as legitimate. When women experience contradictions through suspicions, questions, and truth-seeking gathered from alternative pieces of knowledge, their narratives serve to legitimize their experiential knowledge. Women construct strategies that apprehend power differences created by the myriad risks for breast cancer beyond those that are personally modifiable. Analysis of these phenomena made visible in the narratives provides evidence for women's power, including as knowledge interpreters and producers, as allies in conflict resolution, and as partners in community health and breast cancer prevention strategies.

### **CHAPTER EIGHT**

## **Discussion and Conclusions**

## Discussion

Breast cancer is the most prevalent cancer among women (cancer.ca, 2019). Environmental risks for breast cancer are understudied, underrepresented, and underreported in scientific and mainstream media (Brown et al., 2006; McArthur & Winter, 2014; McArthur, 2015; Ohayon, Nost, Kami, Rakoff & Brody, 2020). As such, they are poorly understood by women (IBCERCC, 2013; NIEHS, 2013). The Ambassador Bridge is the busiest border crossing in North America, where over 20,000 transport trucks and other vehicles cross each day. No formal study has been carried out to document breast cancer incidence at the bridge site despite experiential evidence of a breast cancer cluster and known risk factors, such as high air pollution levels. However, emerging evidence suggests that women employed there are experiencing breast cancer at significantly higher rates than the rest of the county (Gilbertson & Brophy, 2018).

This study, a qualitative inquiry involving women workers at the bridge, provides a unique and significant contribution to women's understanding of breast cancer risk. In particular, the study provides a distinct perspective of risks located in a workplace environment, substantiating health investigations into women's working conditions in relation to breast cancer risk. The study explores the layers influencing meaning-making about environmental breast cancer risks through the expertise of women's subject positions and experiential knowledge.

Kleinman's theoretical approach (1978) grounds subject location and influences, and this approach is further developed in this study by incorporating standpoint theory (Smith, 1979, 1997) and a socioecological framework (Bronfenbrenner, 1977; Schettler, 2015; CHE, 2020). Standpoint theory nested in a socioecological frame enhances subject location and develops the idea of 'what really matters' to apprehend influences on priorities and understandings. Incorporating these multiple perspectives frames women's understandings as situated in their sociocultural contexts and allows for an understanding of subject location and agency for breast cancer risks.

Based on in-depth, individual interviews with twenty-five women who work or have worked at the Ambassador Bridge, the study investigates the knowledge women use to construct breast cancer risk narratives and uncovers interrelationships between knowledge and knowledge sources, and how knowledge sets are presented in narratives. The narratives serve as lenses into socio-cultural conditions and interrelationships between individuals and their environments. Situated in the context of neoliberal ideology, analysis of the narratives reveals the pervasive discourse of individualization of responsibility for health decisions, including breast cancer, narrows explanations of how health knowledge is constructed. The creation and responsibility for risk mitigation strategies are vital aspects of the narratives. Structural inequalities and social determinants of health contribute to breast cancer risk understandings, generating distinctive breast cancer risk narratives addressing gender, money, and power. The women produce understandings of occupational, environmental, and broader social, cultural and economic environments connected to breast cancer risk.

## Key Findings of the Study

The dissertation introduction declares "breast cancer is a social problem where history and biography come together, revealing conditions that illustrate societal values, beliefs and structures." Pivotal to this statement is the idea that women themselves must be involved in creating narratives of history—narratives that garner recognition for their authority on projected futures and implications for public health and workplace policies. By analyzing women workers' narratives from the bridge, greater insight and understanding of the above declaration is realized. Guided by theory, the analysis demonstrates that breast cancer risk understandings are constructed using knowledge from multiple cultural systems, including personal observations, experiential evidence, and explanations of power inequalities in social structures.

Women's narratives identify environmental risks for breast cancer and how the women envision control over these risks. Cultural influences and social location are incorporated into risk narratives. The expressions of breast cancer risk knowledge illuminate the women's biographies and where they intersect with broader sociocultural contexts. Risks for breast cancer are spoken about as community products, and understandings are negotiated using multiple information sources.

Contemplations and visions of agency are imagined using a multiplicity of influences. Professional and medical knowledge of breast health information is incorporated with experiential knowledge as women mediate conflicts and tensions about breast cancer risks. Biomedical discourses and occupational and environmental discourses appeared dichotomous, though the women's narratives located the spaces between, uncovering marginalized risk knowledge. The weaving of information and experience from multiple sources reinforced dominant ideas and produced counter-narratives, exemplifying conflicts in women's socio-ecological relationships. Power and inequalities related to breast cancer risk were identified as having been shaped by socio-cultural conditions.

Many of the women's narratives contain personal breast cancer risk mitigation strategies consistent with the dominant mainstream cultural discourses that frame breast cancer as a personal problem. Personal strategies are present in narratives but are not foremost amongst the controls women discuss when confronting breast cancer risks. As they describe work environments and conditions and broader physical, social, and cultural environments where workplace experiences are situated, women elucidate the complexity of relationships between socio-cultural contexts critical for breast cancer risk mitigation strategies. Narratives draw on the knowledge of environmental exposures related to health and breast cancer specifically and identify barriers and challenges to risk mitigation that illustrate personal strategies' ineffectiveness. Knowledge of interacting systems influencing breast cancer risk contributed to identifying micro through macrolevel strategies. Their development of systems-level strategies adds new knowledge, as prior studies found that despite women's knowledge of environmental risks for breast cancer, they still focused on personal level risk mitigation strategies (Robertson, 2000).

The narratives incorporate challenges to standard breast cancer risk stories, reinforcing other analyses identifying disruptive breast cancer narratives (Nielsen, 2019). Women at the Bridge describe extensive challenges to agency targeting workplace and more comprehensive societal level strategies. In spite of this they communicate optimism and hope that structural changes are possible through advocacy directed at employers, health officials and governments at all levels. Garnering public support for regulatory and legislative changes is an identified component of agency.

Narratives that challenge the hegemonic phenomenology of breast cancer, including the responsibilization of the individual woman for breast cancer, cast women as "agents of meaning-making in the context of unequal power relationships between the person and the world surrounding that person" (Porroche-Escudero, 2011, p. 19). Narratives constructed by women of their breast cancer risk experiences shed light on the structural forces that contribute to breast cancer risk and aspects of the breast cancer experience that the dominant discourses omit or relegate to the margins. The narratives can be explored for "the impact of underlying power dynamics and normative gender constructions on women in relation to illness and narrative" (Nielsen, 2019, p. 44).

The value in identifying and analyzing the power dynamics seen through women's knowledge is the understanding of agency through a broadened conception of adaptive tasks in health. Identifying power and unequal power sites facilitates resolving conflicts in systems for more effective health care strategies. Situating power and differences constructed within the social context and considering the "ways that structures of power such as class, age, gender, and disability, intersect and 'conspire' through a web of social beliefs, practices, norms and expectations to shape, and exacerbate, women's experiences of illness" (Porroche-Escudero, 2011, p. 3) are essential to this process. Narratives of women from the Bridge, as seen through the theoretical framework of women's subject location, their standpoint bringing out how structure impacts agency, illuminates environmental breast cancer risks and risk mitigation strategies.

## Insights and Analysis

The narratives supplied by the women from the bridge illustrate that understandings and perceptions of breast cancer risk are created using a multiplicity of sources. Beliefs, choices, decisions, roles, relationships, interactions, settings, and institutions are all part of information processing. Systems and information sources contribute to risk narratives and illustrate how social and cultural contexts come to bear on understandings and experiences of breast cancer risks. Tensions between sources of information and the transposition of tensions in lived experiences reveal how women make sense of and prioritize understandings.

The analysis illustrates the value of narratives for uncovering tensions, conflicts, and points of resistance (Tangaard, 2009), and reveal understandings of breast cancer risks that biomedical and epidemiological data cannot (Brown, 2003). Theorizing inequalities in health through a lay knowledge lens illustrates nuanced explanations of experiences and understanding of inequalities and environmental risks to health that other forms of data collection and analysis miss (Hesse-Biber, 2012; Messing, 1998). Power and politics in the narratives illustrate the structural and social determinants of health in relation to women's risk experiences (Popay et al., 1998; White et al., 2013; WHO, 2019).

In weaving their stories, women's biographies, life and work experiences, relationships with their co-workers, family, friends, medical professionals, and information sources add to the narratives' socioecological grounding and understanding. As Kathy said, "Put us all together, and pretty soon, you have just got lots of stories that all have the same ending." When assembled, the women's narratives tell a story that contributes new dimensions to occupational and environmental health, specifically breast cancer knowledge.

In constructing risk narratives, women examine their experiences and uncover limitations and barriers to enacting agency. "It is through the process of reflection that individuals examine rules, habits, and traditions that are accepted without question. Insights gained through self-enlightenment are emancipatory in the sense that individuals become conscious of the forces that dominate their lives" (Boulos & Rajacich, 2003, p. 5). Inequalities and social determinants of health are illustrated in breast cancer risk narratives, while power is grappled with in contemplations of agency. The insights illustrate that breast cancer risk control is not merely a choice but is bound by the complexities of social and cultural conflicts that include gender, class, and power. Some women feared their stories would be used as evidence to exclude women from jobs with CBSA. The knowledge of the risks generated in this research should be a catalyst for improved risk management and health and safety strategies that protect women in their jobs, regardless of the industry (Lewis, Maticka-Tyndale, Shaver & Schramm, 2005, p. 163).

Locating narratives of environmental breast cancer risk within social and institutional relationships illustrates meanings and behavioural norms. Women understand and integrate environmental knowledge in narratives, as seen through those relationships and settings. The information facilitates the improvement of knowledge translation strategies, knowledge mobilization, regulatory and policy modification and creation, risk mitigation at the individual and collective level, and setting priorities for future research investment. The social meanings generated in the narratives can contribute to public health strategies that address "the structural violence which systematically exposes some groups to risk while denying social responsibility for that risk...a problem that can be heard echoing through many other settings (Kleinman & Seeman, 2000, p. 231). Women at the Bridge describe how governments and employers fail to acknowledge the social context and structural impacts, including working conditions, on women's health.

## Narrative Typologies in the Study

Distinct narratives typologies (Frank, 1995) are identifiable in women's breast cancer risk stories. The typologies spaces between the dichotomies, transcending the implication of individual volition and exposing the paradox of cancer control, are reflective of subject location, standpoints, and socioecological contexts the women incorporate into understandings of breast cancer risk (see Figure 11). System knowledge, then, is also evident in the understanding of breast cancer risk.

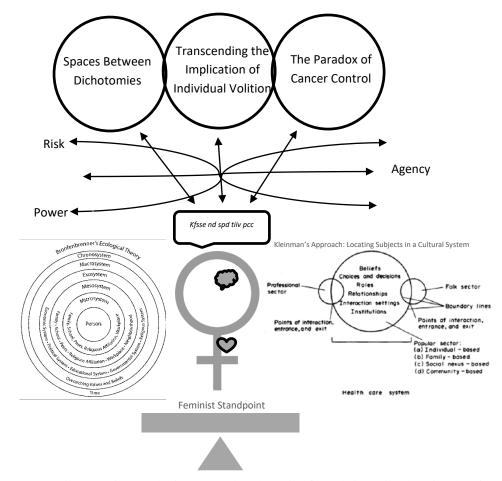


Figure 11: The Production of Breast Cancer Risk Narrative Typologies

Women's breast cancer risk narrative typologies are produced starting from their subject location drawing on multiple information sectors (Kleinman, 1978). Women's standpoint and a feminist lens (Smith, 1974; Collins, 1986) illuminate how structure influences risk understandings and agency as situated in their socioecological framework (Bronfenbrenner, 1977; Schettler, 2015). The narrative typologies produced are filtered through understandings of risk, agency, and power.

The narratives expose the limitations of approaches that lead to a dichotomization of breast cancer risk. The presentation of breast cancer risk as predominantly individual, while obscuring systemic factors, is uncovered in the narrative analysis. The narratives engage and explain the complexity of systemic interactions and ecological environments, drawing out risk discourses typically omitted. The combinations of risk factors, vulnerabilities that exist for specific populations of women, details of distinct environments and working conditions, suspicions and questions that arise from experiences, and lay knowledge in the women's narratives fill the spaces between the dichotomies.

In *transcending the implication of individual volition*, women incorporate environmental risks and involuntary exposure knowledge, underscoring where agency on breast cancer risk is both personal and extends beyond the individual. Women recognize agency is situated, constructed, influenced, and constrained by systems and structures. The women transcend personal action to recognize where socio-ecological environments influence agency. In transcending the boundary of individual control over cancer to exposures emanating in environments—often involuntary and personally non-modifiable exposures—risk strategies imagined in the narratives begin *exposing the paradox of cancer control*. With the prevention of breast cancer, the remainder of the continuum becomes redundant.

Transcendence from the individual and other paradoxes of cancer control are identified in the narratives when discussing money, gender, harmony and compliance, difference, and power. The women experience contradictions in risk knowledge through suspicions, questions, and truth-seeking gathered from alternative knowledge sources, and the production of their risk narratives legitimizes their experiential knowledge. The tensions that emerge in the narratives as they highlight conflict and power disparities illuminate that despite awareness, knowledge, and the identification of environmental risks for breast cancer, the women experience powerlessness. That sense is especially poignant in descriptions of failures of regulatory and legal regimes and concerning involuntary exposures. The women recognize a multiplicity of risk mitigation agents and roles across the socio-ecological levels, including for themselves, management, employers, their community, the Ambassador Bridge Company, and governments. They construct risk strategies that resist and apprehend power differences created by the myriad risks for breast cancer beyond those that are personally modifiable, casting themselves as agents of change. The phenomenon of women's agency apparent in the narratives is evidence of women's power as knowledge interpreters and producers, allies in conflict resolution, and partners in community health and breast cancer prevention strategies. The individual responsibilization of health under neoliberal ideology is paradoxical to the knowledge that the women's experiential knowledge produces.

### Context

Culture works at all levels. It affects health disparities, communication and interactions in the doctor-patient relationship, the illness experience and health care outcomes (Chen, 2009). Though the women in the study did not explicitly frame breast cancer risk at the Ambassador Bridge as a problem of environmental injustice, analysis of their narratives reveals this workforce's vulnerability, showing how power disparities create conditions of inequality that are not easily remedied without structural changes. The lack of a formal study documenting a cluster is also an injustice. Breast cancer risk at the Bridge is a problem of structural forces such as government and public health officials who may be accused of "denying social responsibility for risk" with "a simplified diagnosis of a specific local problem" (Kleinman & Seeman, 2000, p. 231) that instead requires the knowledge of the subjects in their location to address it adequately.

As an occupational cohort, the women at the bridge are disproportionately subjected to higher levels of environmental risks than other workers. Their power as workers and women is disproportionate to managers, employers, governments, and corporations, making them especially vulnerable to health risks. There are structural, societal, and systems-level contributions to breast cancer at the Bridge. Employer, governments, and compensation boards failure to recognize these contributions perpetuates injustice.

The dominant ideology of neoliberalism focuses on the individual, responsibilizing them for health.

Neoliberal ideas value the following: a smaller welfare state, whereby governments do less, and individuals and families are responsible for their own social welfare; the commodification of social goods (e.g., health care, education and welfare services); and economic efficiency to enable an unfettered 'free' market" (Bhuyan, Jeyapal, Ku, Sakamoto & Chou, 2015, p. 50).

This focus obscures socioecological factors contributing to breast cancer risk and societal changes that could address women's risks in their living and working environments. The neoliberal system prioritizes capital movement while also mobilizing breast cancer risk factors, subordinating women's health to its ideology in occupational and other environments.

The narratives appeal to the reclamation of the population-based, preventionfocused roots of public health. A broader view of health that accounts for factors produced by and within the social and cultural context is just, equitable and more healthpromoting. The perspective is captured in the World Health Organization's Ottawa Charter for Health Promotion: Health promotion is the process of enabling people to increase control over, and to improve, their health...not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being... strategies and programs should be adapted to the local needs and possibilities of individual countries and regions to take into account differing social, cultural and economic systems (WHO, 1986).

Framing breast cancer—and women's health generally—with a lens of social context, as opposed to individuals' problem, brings focus to injustices relegated to the margins of discourses on breast cancer. "We can protest and resist a dangerous moral ethos in our families, workplaces and communities...we are morally responsible for ensuring that others understand the social injustice our worlds routinely create, including what we have brought about by our own actions. And we are also responsible for doing something about injustice (Kleinman, 2007, p. 24). The stories of women at the Bridge point to the importance of a public health approach that sees social determinants of health in a socioecological model while moving away from individual responsibilization to recognizing health is a function of all levels of the system.

The narratives gathered in the study illustrate women's knowledge and agency, and the knowledge produced overcomes simplification of the relationship between behaviours and knowledge of environmental breast cancer risks. The application of the "sociological imagination" (C. Wright Mills', 1959) to the problem of environmental breast cancer risk transcends personal experience, illustrating how personal narratives of breast cancer risks are located in a social context, where the personal is influenced and mediated by social dynamics.

# Conclusions

## Contributions of the Study and Recommendations

This study makes several contributions. The research builds on what is known from prior studies about illness narratives, perceptions of risks, breast cancer risk discourses, ambiguities of environmental exposures and associated risk, and information influences on behaviour or other socio-cultural environmental changes. The research addresses gaps in the literature regarding women's agency around breast cancer risks while taking structure and power into account. It contributes to understanding gaps in knowledge translation and mobilization of breast cancer risks, particularly environmental and occupational. The study illuminates women's processing and assessment of risk knowledge and agency at personal, collective and structural levels.

The research contributes theoretically, taking Kleinman's approach to medical systems as cultural systems (Kleinman, 1978), stemming from their utility as an ecological framework grounding subject location, and exposes the limitations of this approach while simultaneously expanding it through the incorporation of feminist standpoint theory (Smith, 1979, 1997) and a socioecological framework (Bronfenbrenner, 1977; Schettler, 2015; CHE, 2020). A feminist standpoint provides a bridge affording an entrée into systemic and structural understandings of health and agency, including social determinants of health and the role of power. Nested in a socioecological frame, further development of 'what really matters' from women's standpoint apprehends influences on priorities and understandings and frames women's knowledge in their socio-cultural contexts. The enhanced theoretical

approach facilitates a deeper understanding of how subject location, agency, and power influence breast cancer risk knowledge.

The research contributes to the understandings of health strategies. In Kleinman's approach, information spheres are conceptualized as independent of each other; the participants in this study bridge the sectors to narrate their experience through adaptive tasks. They illustrate agency as interactions where women incorporate systems-level knowledge connecting the separations and interpolating spaces between spheres. The women's narratives outline the complexity of breast cancer risk understandings shaped through multiple, interrelated and interacting knowledge systems.

The study contributes to identifying the limitations of framing breast cancer risk knowledge as biomedical, located in women's bodies and under women's control. The study's findings and analysis suggest that breast cancer risk is a public health issue nested in broader socioecological structures and relationships. The narrative inquiry and analysis method, including discourse analysis, accounts for social context and produces details and specificity about breast cancer risk contexts. Public health policy and initiatives to address breast cancer risk should also account for these factors. Methodological approaches to understanding breast cancer risk should not be limited to biomedicine and sciences; social science methods, including narrative analysis, make distinctive contributions to breast cancer risk knowledge. The incorporation of a socioecological perspective promotes public health goals.

The study contributes to elucidating how narratives of health risk are constructed and rooted in the subject location. As seen through the analytical framework that privileges subject location, narratives illuminate how understandings of scientific,

234

medical, or epidemiological evidence are incorporated into risk narratives and can present challenges to dominant discourses and hegemonic understandings. Increasing recognition of environmental impacts on health leads to multiple risk factors for health becoming assimilated into risk narratives. The disparate knowledge integration is essential for compelling future health-enhancing strategies. Locating women's environmental and occupational health, specifically, breast cancer enables identifying the nested set of relations that produce risks in a socioecological framework. Improved and better-targeted risk mitigation strategies can produce risk reduction and elimination.

Including lay knowledge and feminist standpoint contributes to nuanced explanations of the multiplicity of risks, including environmental and health inequalities. Lay knowledge and theorizing health inequalities are tools for "mediating the relationship between structural inequalities, individual or group action and health status" (Popay, Williams, Thomas & Gatrell, 1998, p. 621), encompassing social process and the "complex interactive relationship between individual experience, social action and the way in which societies are organized at a macro level" (Popay et al., 1998, p. 629). Women's knowledge contributes to interpretations and insights in an essential partnership in community health and breast cancer prevention strategies.

The study points to the need for the following changes to be implemented:: further epidemiological and other scientific research on the exposures identified by the women, including in exceptionally high traffic volumes, diesel emissions, radiation and shift work; enhancing the accessibility of scientific and other knowledge for the public and, in particular women, and workers at risk for breast cancer; improved policy and regulation in occupational and general environments where exposures are present or suspected; a re-evaluation of accepted forms of evidence, as well as the adoption of the precautionary principle, regarding the work-relatedness of breast cancer by the compensation system; future planning and policy to protect women in similar working environments, including the Gordie Howe International Bridge currently under construction, and strategies to address environmental injustice at the Bridge, other workplaces, and communities worldwide.

Public health considerations of environmental and occupational breast cancer risks emerge from analyzing the women's narratives. Policy, regulation, and risk mitigation strategies are enhanced by understanding how women make meaning in their knowledge of breast cancer risks and how they perceive the possibilities and barriers to agency to mitigate risks. Of particular importance are the challenges issued by women to focus on cancer risk sites and how risk mitigation responsibilities are ascribed. The findings highlight the importance of biographical and social context to breast cancer understandings, particularly the dominant individualization of risk and responsibility and structural inequalities that produce breast cancer risk and influence agency.

The study findings suggest breast cancer risk mitigation strategies should account for the role of culture and power in producing risks, in breast cancer knowledge translation and mobilization, and future research on breast cancer risk communications. A comprehensive approach to breast cancer would incorporate women's knowledge and influence research and service provision beyond the limited scope of focusing on individuals (Kerr, Ross, Jacques & Cunningham-Burley, 2018).

While this study's scope was not inclusive of specific policies, laws, regulations or governance, there are insights drawn from the women's narratives that can provide direction for future programming, policy, legal, regulatory and governance considerations. Micro-, meso-, exo-, macro-, and chrono-level actions should be addressed (Bronfenbrenner 1994). This is consistent with the WHO 2016 Report on Social Determinants of Health. "Actions do not need to come from health alone, but rather from all sectors making decisions that impact on environmental determinants of health. Acting together on coordinated health, environment and development policies can strengthen and sustain improvements to human well-being and quality of life via multiple social and economic co-benefits" (WHO, 2016). The report goes on to claim: "Repositioning the health sector to work more intersectorally on effective preventive health policies is the way forward to address environmental causes of disease and injury, and, ultimately, in transforming the global burden of disease (WHO, 2016).

The WHO focus on environmental risk factors in relation to prevention is elaborated on:

The realization of just how much disease and ill health can be prevented by focusing on environmental risk factors should add impetus to global efforts to encourage preventive health measures through all available policies, strategies, interventions, technologies and knowledge (WHO, 2016).

Specific sectors and their roles are named in the preventive efforts recommended by the WHO: "Armed with the evidence of what is achievable—and needed—health-care policy-makers and practitioners alike should be encouraged in their efforts to promote healthy environments. Our evolving knowledge about environment-health interactions will support the design of more effective preventive public health strategies and

interventions, directed at eliminating health hazards and reducing corresponding risks to health" (WHO, 2016).

Increased research directed at breast cancer's social and environmental causes will correct the overreliance on the biomedical model (Rosser, 2002). Understanding breast cancer risk in a framework that accounts for social and cultural factors and interrogating agency related to these is critical. Knowledge translation, knowledge mobilization, regulatory and policy modification and creation, and risk mitigation strategies that incorporate individual and collective structural factors can resolve problems created by the limitations of exclusively biomedical approaches to cancer prevention. "Thinking about this [breast cancer] as an ecological challenge helps us identify multi-level interventions that will reduce breast cancer risk and improve outcomes" (Schettler, 2014, p. 16). Locating health in a socioecological framework establishes how breast cancer is experienced in a nested set of multi-level and multifactorial relations over the life course. Breast cancer risk mitigation strategies should necessarily reflect this in order to be effective.

The knowledge in the study narratives prompts reiterating the U.S. Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERC) statement that causal environmental factors for breast cancer are "more readily identified and modified than genetic factors and therefore present a tremendous opportunity to prevent breast cancer" (IBCERC, 2013). The analysis of knowledge produced by the women's narratives at the Bridge can facilitate achieving the goal of prevention declared by the IBCERC.

#### Limitations, Strengths and Opportunities for Future Study

The study has limitations. Participation in the study materialized after the publication of an article in *The Windsor Star* about the research. The article may have influenced women's understandings of environmental and occupational breast cancer risk. The women knowingly and willingly volunteered to participate in research about environmental risks for breast cancer. The study findings are not generalizable to all women, as this was a sample of women from a particular workplace at a particular point in time. The women's understanding of breast cancer risks and the related agency is situated in their specific geographical, social, and cultural contexts.

Although the study's scope is a limitation from the perspective of generalizability, the location and workforce specificity provided in the narratives are strengths. One strength is its unique and significant examination of how a highly exposed occupational cohort understands breast cancer causation. The study represents one of the few academic investigations that identify workers' perspectives on cancer's complex nature. The particularities of the exposures, working conditions and practices, institutional knowledge and functions, barriers identified, and risk mitigation opportunities contribute a precise knowledge set regarding the women, working conditions at the Bridge, and breast cancer risk. The knowledge produced can be used as a foundation and catalyst to investigate further the presence of the exposures, the incidence of breast cancer among the workforce, and the actions prescribed to remediate the problems found. The awareness gleaned of how women's understandings are constructed can be generalized and applied through future studies, including applying the methodological and theoretical framework. This study discloses the perception amongst women who work at the Ambassador Bridge that breast cancer rates are elevated. Neither the incidence of breast cancer nor the link to exposures at the bridge can be established based on this study. However, the study provides rich details about how risks and exposures are experienced and understood and the conditions that produce risk understandings. The knowledge produced by the women in this study may not be sufficient alone to create and construct policy, regulation, planning in ways that conform to legal, technical, or scientific requirements, they nonetheless, provide a groundwork for discussion, for consideration, for continued investigation, and consultation on creation and improvement of policy, regulation, and law.

A key finding of this research is the need for formal documentation of the number of breast cancer cases among women who work or have worked at the Bridge. Evidence of conditions and exposures that could be related to elevated breast cancer is presented in narratives. Many women in the study expressed that formal documentation is an essential outcome of this study. Documentation of the cases and the possible cluster would facilitate addressing some of the issues identified, including recognizing breast cancer for compensation purposes, risk mitigation strategies, and future planning for the Gordie Howe Bridge and other workplaces and general environments where concern about exposure to risks for breast cancer are present.

Further investigation is warranted regarding other health problems, diseases, conditions, and concerns mentioned by the women in this study. Such studies need to extend past the workforce to include community members who live in close proximity to the bridge (inclusive of women, men and children) to address the increasing burden of environmental problems.

During the past 40 years, our approaches to cancer prevention had limited success, whereas the scientific understanding of the complex process of cancer development has advanced to provide new insights into causation and prevention. New approaches to cancer prevention must use this expanded scientific knowledge and our understanding of the interplay between various cancer risk factors at multiple levels within a particular social and historical setting...Likewise, a better understanding is needed on how social, economic, and environmental circumstances can influence, support or limit "lifestyle" and other behaviours at different stages of life (White et al., 2013, p. 8).

This study apprehends the opportunity to fulfill some of this vision and encourages continued similar approaches to achieve the above goals.

Increased understanding and collaborative partnerships between medical science and social science could improve breast cancer prevention strategies, particularly where risks are related to involuntary, environmental exposures. The way women understand breast cancer risk is dynamic, contextualized, multisectoral, and relational and offers insights into understanding spaces. As seen from women's standpoint, breast cancer risk is not solely a biomedical phenomenon residing in the body, determined by genetics or lifestyle choices, but is experienced by women in a nested set of social, cultural. and political relationships. Dominant biomedical narratives obscure the experiences of the women, including the spaces they identify breast cancer risks. Women are important knowledge producers and interpreters and should be included as partners and collaborators in public health and breast cancer prevention strategies.

Understanding the health system as a cultural system frames health and wellness as an interaction of the whole's parts. Socioecological models point to that understanding, whether for breast cancer, intimate partner violence, poverty, addiction, climate change and more. The women at the Bridge recognize the nestedness of their breast cancer risks and their visions for agency. As Cindy said, "Sometimes, you just need someone to plant the right seed about things."

Breast cancer is "a design problem. It is not only a disease of abnormal cells but also of communities that we create and live in. Breast cancer is profoundly a public health concern, requiring a public health response" (Schettler, 2014). There is a need for fundamental social change to stem the breast cancer epidemic. "Such change would include reframing how scientific research is conducted, making prevention rather than cure the goal of both research and clinical practice, eliminating corporate interests in making profits from the disease, and breaking the silence about environmental connections to breast cancer (Kasper & Ferguson, 2002, p. 356). Breast cancer risk narratives of the women at the Bridge are stories of power from the margins that point to critical interventions necessary for environmental breast cancer risk mitigation.

#### REFERENCES

- Adler, P. & Adler, P. (2008). Four Faces of Ethnography. *Sociological Quarterly*. Volume 49, Issue 1, pages 1–30, Winter 2008.
- Aduayi, V., Onayade, A., Aduayi, O., & Odu, O. (2015). Relating self-perceived with objective risk for breast cancer among women in rural and urban communities in southwestern Nigeria. *International Journal of Medical Science and Public Health*, 4(10), 1449. DOI: 10.5455/ijmsph.2015.02052015299
- Alasuutari, P. (2010). The rise and relevance of qualitative research. *International Journal of Social Research Methodology*, *13*(2), 139-155. DOI: 10.1080/1364557090296605
- Allmark, A. & Tod, A. (2006). How should public health professionals engage with lay epidemiology?. *Journal of Medical Ethics*. Aug; 32(8): 460–46.
  DOI: 10.1136/jme.2005.014035
- Altheide, D & J. Johnson. (2011). Reflections on Interpretive Adequacy in Qualitative Research. In *The Sage Handbook of Qualitative Research* (pp 581-94). Thousand Oaks,.
- Andsager, J., & Powers, A. (1999). Social or Economic Concerns: How News and Women's Magazines Framed Breast Cancer in the 1990s. *Journalism & Mass Communication Quarterly*, 76(3), 531-550. DOI: 10.1177/107769909907600309
- Armstrong, P. & Pederson, A. (2015). Women's Health. Women's Press.
- Ashton, C., Haidet, P., Paterniti, D., Collins, T., Gordon, H., & O'Malley, K. et al. (2003). Racial and ethnic disparities in the use of health services. *Journal of General Internal Medicine*, 18(2), 146-152. DOI: 10.1046/j.1525-1497.2003.20532.x

- Atari, D., & Luginaah, I. (2009). Assessing the distribution of volatile organic compounds using land use regression in Sarnia, "Chemical Valley," Ontario, Canada. *Environmental Health*, 8(1). DOI: 10.1186/1476-069x-8-16
- Atkin, C., & Smith, S. (2010). Improving Communication Practices to Reduce Breast Cancer
  Environmental Risks. *Health Communication*, 25(6-7), 587-588. DOI:
  10.1080/10410236.2010.496836
- Atkin, C., Smith, S., McFeters, C., & Ferguson, V. (2008). A Comprehensive Analysis of Breast Cancer News Coverage in Leading Media Outlets Focusing on Environmental Risks and Prevention. *Journal of Health Communication*, *13*(1), 3-19. DOI: 10.1080/10810730701806912
- Atkinson, S. & Rubinelli, S. (2012). Narrative in cancer research and policy: voice, knowledge and context. *Critical Reviews in Oncology/Hematology* S11-S16.

Back, Les. (2007). The Art of Listening. Berg: New York, New York.

- Barnoya, J. & S. Glantz. (2004). Association of the California Tobacco Control Program with Declines in Lung Cancer Incidence. *Cancer Causes and Control*. September 2004, 689-695.
- Basco, P. & Wardle, H. (2007). How to Read Ethnography. London: Routledge.
- Batt, S. (2017). *Health Advocacy Inc.: How Pharmaceutical Funding Changed the Breast Cancer Movement*. UBC Press: Vancouver, Toronto.
- Beck, M., & Kewell, B (2004). Risk: A Study of its Origins, History and Politics. World Scientific Publishing, Singapore.

- Becker, H. (2000). Afterward: Racism and the Research Process. In Twine, France Widdance and Jonathan Warren (Eds.), Researching Race: Methodological Dilemmas in Critical Race Studies. New York: NYU Press: 247-254
- Bedeau, K. (2006). Perceptions of health and environmental contamination on the Aamjiwnaang First Nation reserve (Ontario) (MA). Electronic Theses and Dissertations. Paper 3035. <u>http://scholar.uwindsor.ca/etd/3035</u>.
- Benton, T. & Craib, I. (2011). Philosophy of Social Science: The Philosophical Foundations of Social Thought, Second Edition. Palgrave Macmillan, New York.

Berger, P. & Luckmann, T. (1966). The Social Construction of Reality. Doubleday, New York.

- Bhuyan, R., Jeyapal, D., Ku, J., Sakamoto, I., & Chou, E. (2015). Branding 'Canadian
  Experience' in Immigration Policy: Nation Building in a Neoliberal Era. *Journal Of International Migration And Integration*, 18(1), 47-62. DOI: 10.1007/s12134-015-0467-4
- Biehl, J, Good, B.J. & Kleinman, A. (Eds.), (2007). Subjectivity: Ethnographic Investigations.Berkeley: University of California Press.
- Boulos, P. & Rajacich, D. (2003). Critical Theory as a Philosophical Base for Nursing Science, *Guidance & Counseling*; Fall 2003, Vol. 19, Issue 1, p3.
- Bratton, J., & Denham, D. (2014). Capitalism and Classical Social Theory. University of Toronto Press Incorporated, Toronto, Canada.
- Breast Cancer Action (2019). "Overview," https://www.bcaction.org/our-take-on-breastcancer/environment/, accessed August 2, 2019.

- Brody, J.G., Moysich, K.B, Humblet, O.H, Attfield, K.R., Beehler, G.P., & A. Rudel, R. (2007).
  "Environmental Pollutants and Breast Cancer: Epidemiologic Studies." *Cancer* 109, no.
  S12 2667-2711.
- Bronfenbrenner, U. (1994). Ecological models of human development. In *International Encyclopedia of Education* (Vol. 3, 2nd ed.). Oxford: Elsevier.
- Brophy J.T., Keith, M.M., Gorey, K.M., Laukkanen, E., Hellyer, D., Watterson A., Reinhartz,
  A., & Gilberston, M. (2002). Occupational histories of cancer patients in a Canadian cancer treatment centre and the generated hypothesis regarding breast cancer and farming. *International Journal of Occupational and Environmental Health*, 8:346-353.
- Brophy, J., Keith, M., Gorey, K., Luginaah, I., Laukkenen, E., & Hellyer, D. et al. (2006).
  Occupation and Breast Cancer: A Canadian Case-Control Study. *Annals Of The New York Academy Of Sciences*, *1076*(1), 765-777. DOI: 10.1196/annals.1371.019
- Brophy, J., Keith, M., Watterson, A., Gilbertson, M., & Beck, M. (2012). Farm work in Ontario and breast cancer risk. In B. Leipert, B. Leach & W. Thurston, (Eds.), *Rural Women's Health*. Toronto: University of Toronto Press.
- Brophy, J., Keith, M., Watterson, A., Park, R., Gilbertson, M., & Maticka-Tyndale, E. et al. (2012). Breast cancer risk in relation to occupations with exposure to carcinogens and endocrine disruptors: A Canadian case-control study. *Environmental Health*, *11*(1). DOI: 10.1186/1476-069x-11-87
- Brown, P. (2003). Qualitative methods in environmental health research. *Environmental Health Perspectives*, *111*(14), 1789-1798. DOI: 10.1289/ehp.6196

- Brown, P., McCormick, S., Mayer, B., Zavestoski, S., Morello-Frosch, R., Altman, R., & Senier,
  L. (2006). "A Lab of Our Own." *Science, Technology, & Human Values, 31*(5), 499-536.
  DOI: 10.1177/0162243906289610
- Brown, P., Zavestoski, S., McCormick, S., Mandelbaum, J., & Luebke, T. (2001). Print media coverage of environmental causation of breast cancer. *Sociology Of Health &Amp; Illness*, 23(6), 747-775. DOI: 10.1111/1467-9566.00274
- Brown, P. (2010). Qualitative Approaches for Studying Environmental Health, *The SAGE Handbook of Qualitative Methods in Health Research SAGE Publications* Ltd City: London.

Brown, W. (2015). Undoing the Demos. Zone Books, Brooklyn, New York.

- Cancer.ca. (2019). [online] Available at: http://www.cancer.ca/Canadian-Cancer-Statistics-2018-EN [Accessed 15 Aug. 2019].
- Cancer.org (2020). [online] Available at: https://www.cancer.org/cancer/cancer-causes/generalinfo/cancer-clusters.html [Accessed May 18, 2020].

Carroll, W. (2004). Critical strategies for social research. Toronto: Canadian Scholars' Press.

- Carroll, W.K, (2010). You Are Here: Interview with Dorothy E. Smith, *Socialist Studies*, 6(2) Fall 2010:9:37.
- Carson, R. (1962) Silent Spring. Houghton Mifflin Harcourt: USA.

- Castel, R. (1991) 'From dangerousness to risk,' In G. Burchell, C. Gordon and P. Miller (Eds)The Foucault Effect: Studies in Governmentality, Hemel Hempstead: HarvesterWheatsheaf: 281-98.
- CBCF (Canadian Breast Cancer Foundation). (2015). *Canadian Cancer Society's Steering Committee on Cancer Statistics*. Toronto, ON: Canadian Cancer Society.
- Chalaby, J. (1996). Beyond the Prison-House of Language: Discourse as a Sociological Concept. British Journal of Sociology 47(4):684.

Champion, C., Berry, T., Kingsley, B., & Spence, J. (2016). Pink Ribbons and Red Dresses: A Mixed Methods Content Analysis of Media Coverage of Breast Cancer and Heart Disease. *Health Communication*, *31*(10), 1242-1249. DOI: 10.1080/10410236.2015.1050082

- Charmaz, K. (2011). Grounded Theory Methods in Social Justice Research. In N. K. Denzin &
  Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (4th edition, pp. 359-380). Thousand Oaks: Sage.
- Chase, S.E. (2008). Narrative Inquiry: Multiple Lenses, Approaches, Voices. In N.K. Denzin & Lincoln, *Collecting and Interpreting Qualitative Materials* (3rd ed.) 57-94. Thousand Oaks, CA: Sage.
- Chen, P. (2009). Bridging the Culture Gap, The New York Times, July 16, 2009.
- Cho, J. & Trent, A. (2006). Validity in qualitative research revisited. *Qualitative Research*, 4(1-2), 127-144.

- Christians, C. G. (2007). Cultural Continuity as an Ethical Imperative. *Qualitative Inquiry*, 13(3), 437-444.
- Clement, W. & Myles, J. (1994). *Relations of ruling: Class and gender in postindustrial societies*. McGill-Queen's University Press.
- Collins, P.H. (1986). Learning from the Outsider Within: The Sociological Significance of Black Feminist Thought, *Social Problems*, Volume 33, Issue 6, 1 December 1986, Pages s14– s32, https://doi.org/10.2307/800672
- Collins, P.H. (1990). Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment (Boston: Unwin Hyman, 1990), pp. 221–238.
- Creswell, J.W. (2011). 'Controversies in Mixed Methods Research, in *The Sage Handbook of Qualitative Research*, Thousand Oaks p. 269-84.
- Crouse, D., Peters, P., Hystad, P., Brook, J., van Donkelaar, A., & Martin, R. et al. (2015).
  Ambient PM 2.5, O3, and NO2 Exposures and Associations with Mortality over 16 Years of Follow-Up in the Canadian Census Health and Environment Cohort (CanCHEC). *Environmental Health Perspectives*, *123*(11), 1180-1186. DOI: 10.1289/ehp.1409276
- Crouse, D., Peters, P., van Donkelaar, A., Goldberg, M., Villeneuve, P., & Brion, O. et al.
  (2012). Risk of Nonaccidental and Cardiovascular Mortality in Relation to Long-term
  Exposure to Low Concentrations of Fine Particulate Matter: A Canadian National-Level
  Cohort Study, *Environmental Health Perspectives*, 120(5): 708–714.

- Cruikshank, B. (1999). *The Will to Empower: Democratic Citizens and Other Subjects*. Cornell University Press, Ithaca, New York.
- Davis, E. (2008). Risky Business: Medical Discourse, Breast Cancer, and Narrative. *Qualitative Health Research*, *18*(1), 65-76. DOI: 10.1177/1049732307309002
- DeMatteo. R, Keith. MM, Brophy. JT, Wordsworth. A, Watterson. A, Beck. M, Rochon Ford, A, Gilbertson, M, Phartiyal, J, Rootham, M, Scott, D. (2012). Chemical Exposures of Women Workers in the Plastics Industry with Particular Reference to Breast Cancer and Reproductive Hazards. *New Solutions*, 22(4):427-448. DOI: http://dx.doi.org/10.2190/NS.22.4.d http://baywood.com
- Denzin, N. (2011) The Politics of Evidence', In *The Sage Handbook of Qualitative Research*, Thousand Oaks, p. 645-58.
- Dias, J., Dias, J., & Zanotti, E. (2018). Reflection on Health Indicators for Atmospheric Chemical Pollutants. *The Academic Society Journal*, 128-138. DOI: 10.32640/tasj.2018.3.128
- DiCicco-Bloom, B., & Crabtree, B. (2006). The qualitative research interview. *Medical Education*, 40(4), 314-321. DOI: 10.1111/j.1365-2929.2006.02418.x
- Dunk, T., (2003) It's A Working Man's Town: Male Working-Class Culture. 2nd Edition. Canada: McGill-Queen's University Press.
- Edwards, R. & Mauthner, M. (2012). *Ethics and Feminist Research: Theory and Practice*. In T. Miller, M. Birch, M. Mauthner, & J. Jessop (Eds.), Ethics in Qualitative Research 2nd ed., pp. 14–28.

- Ehrenreich, B. (2001). Welcome to Cancerland: A mammogram leads to a cult of pink kitsch. *Harper's Magazine*, USA.
- Emirbayer, M., & Mische, A. (1998). What Is Agency?. *American Journal Of Sociology*, *103*(4), 962-1023. DOI: 10.1086/231294
- Engel, C.L., Rasanayagam, S. & Gray, J.M. (2018). Work and Breast Cancer: Recommendations to Address Research Needs, *New Solutions: A Journal of Environmental and Occupational and Health Policy*. Volume: 28 issue: 1, page(s): 79-95, https://doi.org/10.1177/1048291118758713
- European Environment Agency. (2001). Late lessons from early warnings: the precautionary principle 1896-2000, *Environmental issue report No 22* [Accessed Sept. 15, 2012, http://www.eea.europa.eu/publications/environmental\_issue\_report\_2001\_22].
- Fahlquist, J. (2009). Moral Responsibility for Environmental Problems—Individual or
   Institutional? *Journal of Agricultural and Environmental Ethics*, Volume 22, pages109–
   124.
- Fairclough, N. (2003) Analyzing Discourse: Textual Analysis for Social Science. New York: Routledge.
- Fancher, T., Ton, H., Le Meyer, O., Ho, T., & Paterniti, D. (2009). Discussing Depression with Vietnamese American Patients. *Journal Of Immigrant And Minority Health*, *12*(2), 263-266. DOI: 10.1007/s10903-009-9234-y

- Feilzer, M. Y. (2010). Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. *Journal of Mixed Methods Research*, 4, 6-16.
- Fontana, A. & Frey, J (2005.) The interview: From Neutral Stance to Political Involvement. In Denzin & Yvonne Lincoln eds., in *The Sage Handbook of Qualitative Research*, Thousand Oaks, pp.695-727.
- Foucault, M. (1973). The Birth of the Clinic. Routledge, USA.
- Foucault, M. (2003). *The Essential Foucault*. Paul Rabinow & Nicolas Rose (Eds.) New York: The New Press.
- Foucault, M. (2004). *The Birth of Biopolitics: Lectures at the Colleges de France 1978-1979*. Picador, New York, New York.
- Frank, A. (1995). The Wounded Storyteller. Chicago: University of Chicago Press.
- Frank, A. (2002). *At the Will of the Body: Reflections on Illness*. USA: Houghton Mifflin Company.
- Fraser, N. (1998). *Redistribution or Recognition? A Political-Philosophical Exchange*. (coauthored with Axel Honneth). London: Verso, 1998.
- French, D., Cameron, E., Benton, Deaton, C. & Harvie, M. (2017). Can Communicating Personalised Disease Risk Promote Healthy Behaviour Change? A Systematic Review of Systematic Reviews, *Annals of Behavioural Medicine*. Volume 51, Issue 5, October 2017, Pages 718–729. https://doi.org/10.1007/s12160-017-9895-z

- Frickel, S., Gibbon, S. Howard, J. Kempner, J. Ottinger, G. & Hess, D.J. (2010). Undone Science: Charting Social Movement and Civil Society Challenges to Research Agenda Setting. Science, Technology, & Human Values 35(4) 444-473.
- Garland, D.W. (2002). *The Rise of Risk. In Risk and Mortality* (Aaron Doyle and Richard V. Ericson, ed., University of Toronto Press.
- Garner, R. (2001). *Social Theory: Continuity and Confrontation, A Reader*. Broadview Press, Toronto, Ontario.
- Garrison, K. (2007). The Personal is Rhetorical: War, Protest, and Peace in Breast Cancer Narratives. *Disability Studies Quarterly*, 27(4). DOI: 10.18061/dsq.v27i4.52
- Gilbertson, M., & Brophy, J. (2001). Community Health Profile of Windsor, Ontario, Canada:
  Anatomy of a Great Lakes Area of Concern. *Environmental Health Perspectives*, *109*, 827. DOI: 10.2307/3454645
- Gilbertson, M., & Brophy, J. (2018). Causality Advocacy: Workers' Compensation Cases as Resources for Identifying and Preventing Diseases of Modernity. *NEW SOLUTIONS: A Journal Of Environmental And Occupational Health Policy*, 28(4), 704-725. DOI: 10.1177/1048291118810900
- Gomez, S., Quach, T., Horn-Ross, P., Pham, J., Cockburn, M., & Chang, E. et al. (2010). Hidden Breast Cancer Disparities in Asian Women: Disaggregating Incidence Rates by Ethnicity and Migrant Status. *American Journal Of Public Health*, *100*(S1), S125-S131. DOI: 10.2105/ajph.2009.163931

- Goodman SN, Samet JM. (2006). Cause and cancer epidemiology. In: Schottenfeld D, Fraumeni JF, (Eds). *Cancer Epidemiology and Prevention*. New York, NY: Oxford University Press; pp. 3–9.
- Goodwin, J. & Horowitz, R. (2002). Introduction: The Methodological Strengths and Dilemmas of Qualitative Sociology. *Qualitative Sociology* 25(1):33-47.
- Grant, T. & Balkissoon, D. (2019). How Canada's racial data gaps can be hazardous to your Health, *The Globe and Mail*, February 11.
- Gray, J., Evans, N., Taylor, B., Rizzo, J., & Walker, M. (2009). State of the Evidence: The Connection Between Breast Cancer and the Environment. *International Journal Of Occupational And Environmental Health*, 15(1), 43-78. DOI: 10.1179/107735209799449761
- Gray, J., Rasanayagam, S., Engel, C., & Rizzo, J. (2017). State of the evidence 2017: an update on the connection between breast cancer and the environment. *Environmental Health*, 16(1). DOI: 10.1186/s12940-017-0287-4
- Green, A., Hayman, L., & Cooley, M. (2015). Multiple Health Behavior Change in Adults with or at Risk for Cancer: A Systematic Review. *American Journal Of Health Behavior*, 39(3), 380-394. DOI: 10.5993/ajhb.39.3.11
- Gutting, G. (1989). *Michel Foucault's Archaeology of Scientific Reason*, Cambridge University Press, USA.
- Hall, R.H. (2003). Breast Cancer: An Environmental Disease, The Case for Primary Prevention, www.nomorebreastcance.org.uk/Main\_v1.pdf

- Henriksen, M., Guassora, A., & Brodersen, J. (2015). Preconceptions influence women's perceptions of information on breast cancer screening: a qualitative study. *BMC Research Notes*, 8(1). DOI: 10.1186/s13104-015-1327-1
- Henry, S., Paterniti, D., Feng, B., Iosif, A., Kravitz, R., & Weinberg, G. et al. (2019). Patients' Experience With Opioid Tapering: A Conceptual Model With Recommendations for Clinicians. *The Journal Of Pain*, 20(2), 181-191. DOI: 10.1016/j.jpain.2018.09.001

Hesse-Biber, C. (2013). The Handbook of Feminist Research. Sage Publications In., California.

- Hesse-Biber, C. & Nagy, S. (2010). Mixed Methods Research: Merging Theory with Practice. New York: The Guilford Press. Chapter 2.
- Hill, S. (2018). Researcher seeks 20 women for breast cancer study, *The Windsor Star*, May 15. https://windsorstar.com/news/local-news/researcher-seeks-20-women-for-breast-cancerstudy
- Ho, Wing-Chung. (2008). Writing experience: does ethnography convey a crisis of representation and ontological break with the everyday world. *Canadian Review of Sociology*, 45(4):343-365.
- Hollands, French, Griffin, Prevost, Sutton, King, Marteau. (2016). The impact of communicating genetic risks of disease on risk-reducing health behaviour: systematic review with metaanalysis, *BMJ* 2016; 352 DOI: https://doi.org/10.1136/bmj.i1102

Holstein, J. A. & Gubrium, J. F. (1995). The Active Interview. Thousand Oaks: Sage.

Holstein, J. & Gubrium, J. (2011). The Constructionist Analytics of Interpretive Practice, in *The Sage Handbook of Qualitative Research*, Thousand Oaks, p. 341-254.

- Honkasalo, M., & Lindquist, J. (1997). An interview with Arthur Kleinman. *Ethnos*, 62(3-4), 107-126. DOI: 10.1080/00141844.1997.9981554
- Hopwood, P. (2000). Breast cancer risk perception: what do we know and understand? *Breast Cancer Research*, 2(6). DOI: 10.1186/bcr83
- Hystad, P., Demers, P., Johnson, K., Carpiano, R., & Brauer, M. (2014). Residential Air
  Pollution and Lung Cancer. *Epidemiology*, 25(1), 159-160. DOI:
  10.1097/ede.00000000000012
- Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERC). (2013). *Breast Cancer and the Environment: Prioritizing Prevention*. Retrieved from http://www.niehs.nih.gov/about/boards/ibcercc/
- International Agency for Research on Cancer (IARC), (2000). Ionizing radiation, part 1: X- and gamma-radiation, and neutrons. Overall introduction. IARC Monogr Eval Carcinog Risks Hum 75 Pt 1. 2000:35–115.
- Jessop, B. (2007). "From micro-powers to governmentality: Foucault's work on statehood, state formation, statecraft and state power." *Political Geography* 26 (2007) 34-40.
- Jones, C. & Porter, R. (Eds.), (1994) *Reassessing Foucault: Power Medicine and the Body*, Routledge, London and New York.
- Jones, S. (2004). Coverage of Breast Cancer in the Australian Print Media Does Advertising and Editorial Coverage Reflect Correct Social Marketing Messages?. *Journal Of Health Communication*, 9(4), 309-325. DOI: 10.1080/10810730490468441

- Karpinski, E.C. (2013). Onco-Filmographics: The Politics and Affects of the Canadian Breast Cancer Documentary Tulsa Studies in Women's Literature, The University of Tulsa Volume 32, Number 2, Fall 2013 / Volume 33, Number 1, Spring 2014 pp. 163-187.
- Katapodi, M., Facione, N., Humphreys, J., & Dodd, M. (2005). Perceived breast cancer risk: heuristic reasoning and search for a dominance structure. *Social Science & Medicine*, 60(2), 421-432. DOI: 10.1016/j.socscimed.2004.05.014
- Rodgers, K.M & Udesky, J.O., Rudel, R.A., Green Brody, J. (2018). Environmental chemicals and breast cancer: An updated review of epidemiological literature informed by biological mechanism, *Environmental Research*, Volume 160, January 2018, Pages 152-182, https://doi.org/10.1016/j.envres.2017.08.045
- Kemmis, S., & McTaggart, R. (2000). Participatory Action research. In *Handbook of Qualitative Research*, 2nd edition, Norman K.Denzin & Yvonna S. Lincoln (Eds). Thousand Oaks, CA: Sage, Pp. 567-605.
- Kerr, A., Ross, E., Jacques, G., & Cunningham-Burley, S. (2018). The sociology of cancer: a decade of research. *Sociology Of Health & Illness*, 40(3), 552-576. DOI: 10.1111/1467-9566.12662
- Kincheloe, J. L. & McLaren, P. (2008). *Rethinking Critical Theory and Qualitative Research*. In
  N. K. Denzin & Y. S. Lincoln (Eds.), The Landscape of Qualitative Research (3rd edition) (pp. 403-455). Thousand Oaks, CA: Sage.

- Klawiter, M. (2004). Breast cancer in two regimes: the impact of social movements on illness experience. *Sociology Of Health And Illness*, *26*(6), 845-874. DOI: 10.1111/j.1467-9566.2004.421\_1.x
- Klawiter, M. (2008). *The biopolitics of breast cancer: changing cultures of disease and activism*. Minneapolis: University of Minnesota Press.
- Kleinman A., Eisenberg L., Good B. (1978). Culture, illness, and care: clinical lessons from anthropological and cross-cultural research. *Ann Intern Med*, 1978;88:251–88.
- Kleinman, A. & Seeman, D. (2000). "The Personal Experience of Illness" in Albrecht, G.L.,Fitzpatrick, R. & Scrimshaw, S. *The Handbook of Social Studies in health and Medicine*.Sage publications: London. P. 230-242.
- Kleinman, A. (1978). Concepts and a model for the comparison of medical systems as cultural systems. *Social Science & Medicine. Part B: Medical Anthropology*, *12*, 85-93. DOI: 10.1016/0160-7987(78)90014-5
- Kleinman, A. (1997). "Everything That Really Matters": Social Suffering, Subjectivity, and the Remaking of Human Experience in a Disordering World. *Harvard Theological Review*, 90(3), 315-336. DOI: 10.1017/s0017816000006374

Kleinman, A. (2007). What Really Matters. Oxford: Oxford University Press.

Kleinman, A., & Kleinman, J. (1991). Suffering and its professional transformation: toward an ethnography of interpersonal experience. *Culture, Medicine And Psychiatry*, 15(3), 275-275. DOI: 10.1007/bf00046540

- Kleinman, A., Eisenberg, L., & Good, B. (2006). Culture, Illness, and Care: Clinical Lessons
  From Anthropologic and Cross-Cultural Research. *FOCUS*, 4(1), 140-149. DOI: 10.1176/foc.4.1.140
- Kolker, E. (2004). Framing as a cultural resource in health social movements: funding activism and the breast cancer movement in the US 1990-1993. *Sociology Of Health And Illness*, *26*(6), 820-844. DOI: 10.1111/j.0141-9889.2004.00420.x
- Kopnina & Keune. (2010), *Health and Environment: Social Science Perspectives*. Nova Science Publishers Inc, New York.
- Krewski, D., Lemyre, L., Turner, M., Lee, J., Dallaire, C., & Bouchard, L. et al. (2008). Public perception of population health risks in Canada: Risk perception beliefs. *Health, Risk & Society*, *10*(2), 167-179. DOI: 10.1080/13698570801919830
- Kriebel D., Tickner, J., Epstein, P., Lemons, P., Levins, R., Loechler, E.L., Quinn, M., Rudel, R.,
  Schettler, T. & Stoto, M. (2001). The precautionary principle in environmental science. *Envir*onmental Health Perspectives,
  https://ehp.niehs.nih.gov/doi/abs/10.1289/ehp.01109871
- Krieger, S. (1985). "Beyond "Subjectivity": The Use of the Self in Social Science." *Qualitative Sociology* 8(4):309-24.
- LeDuff, C. (2018). Ambassador Bridge owner Manuel (Matty) Moroun eyes 'twilight deal' as his son rises. *Detroit Free Press*.
- Lemke, Thomas (2002). Foucault, Governmentality and Critique, *Rethinking Marxism*, Volume 14, Number 3, Fall 2002.

- Lewis, J., Maticka-Tyndale, E., Shaver, F., & Schramm, H. (2005). Managing Risk and Safety on the Job. *Journal Of Psychology & Human Sexuality*, 17(1-2), 147-167. DOI: 10.1300/j056v17n01\_09
- Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic Controversies,
  Contradictions, and Emerging Confluences Revisited. In N. Denzin, & Y. S. Lincoln
  (Eds.), *The Sage Handbook of Qualitative Research* (4th edition, pp. 97-128). Thousand
  Oaks: Sage.
- Lincoln, Y., & Tierney, W. (2004). Qualitative research and institutional review boards. *Qualitative Inquiry*, 10(2), 219-234. DOI:10.1177/1077800403262361
- Lippel, K. (2008). "Workers' Compensation and Controversial Illnesses" In Moss, Pamela and Teghtsoonian, Katherine (Eds.), *Contesting Illness: Processes and Practices* University of Toronto Press.
- Lofland, J. & Lofland, L. (1995). *Analyzing Social Settings*, University of California Davis, USA.
- Lougheed, T. (2014). Arising from the Ashes? Environmental Health in Detroit. *Environmental Health Perspectives*, *122*(12). DOI: 10.1289/ehp.122-a324
- Luginaah, I., Gorey, K., Oiamo, T., Tang, K., Holowaty, E., Hamm, C., & Wright, F. (2012). A geographical analysis of breast cancer clustering in southern Ontario: generating hypotheses on environmental influences. *International Journal Of Environmental Health Research*, 22(3), 232-248. DOI: 10.1080/09603123.2011.634386

- Lupton, D. (1994). Femininity, Responsibility, and the Technological Imperative: Discourses on Breast Cancer in the Australian Press. *International Journal Of Health Services*, 24(1), 73-89. DOI: 10.2190/1b6j-1p5r-axcr-mrny
- Marmot, D & Wilkinson, R. (2005). Social Determinants of Health, OUP Oxford Medical.
- Marteau, T.M & Lerman, C. (2001). Genetic risk and behavioural change. *BMJ British Medical Journal*, 322:1056.
- Mascia-Lees, F., Sharpe, P. & Ballerino Cohen, C. (1989). The Postmodern Turn in Anthropology: Cautions From a Feminist Perspective. *Signs* 15 (1): 7-33.
- Mauthner, N. S. & Doucet, A. (2003). Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis. *Sociology*, 37, 413-431.
- McArthur, J.E. & Winter, J. (2014). Toronto Star Coverage of the Politics of Breast Cancer. *Synaesthesia*, Summer, 1-16.
- McArthur, J.E., "The Toronto Star and the politics of breast cancer" (2014). *Electronic Theses and Dissertations*. Paper 5033.
- McArthur, J. (2018) Challenging the Dominant Breast Cancer Causation Paradigm through the Lens of Media Discourses In *Sick and Tired: Health and Safety Inequalities*. (S. Premiji, Ed.), Fernwood Publishing, Labour in Canada Series.
- McGannon, K., Berry, T. Rodgers, K. Spence, J. (2016). Breast Cancer Representations in Canadian News Media: A critical discourse analysis of meanings and the implications for identity, *Qualitative Research in Psychology*, Vol. 13, No. 2, 188-207.

- McGarity, T. O. & Wagner, W.E. (2008). *Bending Science: How Special Interests Corrupt Public Health Research*. Harvard University Press, USA.
- McKinnon, M. (2014). "Ontario Fire Fighters Applaud New Presumptive Regulations," Ontario Professional Fire Fighters Press Release.

Messing, K. (1998). One-eyed science. Philadelphia: Temple University Press.

- Michaels, & Monforton (2005). Manufacturing Uncertainty: Contested Science and the
  Protection of the Public Health and Environment. *Am J Public Health*, 2005;95 Suppl 1:S39-48. DOI: 10.2105/AJPH.2004.043059
- Michaels, D. (2006). Manufactured Uncertainty: Protecting Public Health in the Age of Contested Science and Product Defense. Annals of the New York Academy of Science. 2006 Sep;1076:149-62. DOI: 10.1196/annals.1371.058.
- Mills, C. W. (1959). *The Sociological Imagination*. Oxford [New York]: Oxford University Press.
- Mordukhovich, I., Beyea, J., Herring, A., Hatch, M., Stellman, S., & Teitelbaum, S. et al. (2016).
  Polymorphisms in DNA repair genes, traffic-related polycyclic aromatic hydrocarbon
  exposure and breast cancer incidence. *International Journal Of Cancer*, *139*(2), 310-321.
  DOI: 10.1002/ijc.30079
- Morello-Frosch R, Brown P, Brody JG, Altman RG, Rudel RA, Zota AR, Pérez C. (2011).
   Exerts, Ethics, and Environmental Justice: Communicating and Contesting Results from
   Personal Exposure Science. In: Ottinger G, Cohen B, (Eds.), *Environmental Justice and*

*the Transformation of Science and Engineering*. Cambridge, MA: MIT Press; 2011. pp. 93–118

- Neale J. (2016). Iterative categorization (IC): a systematic technique for analyzing qualitative data. *Addiction*. 111: 1096–1106. DOI: 10.1111/add.13314
- Nelissen, S., Beullens, K., Lemal, M., & Van den Bulck, J. (2015). Media use, cancer knowledge and lifestyle choices: a cross-sectional analysis. *The European Journal Of Public Health*, 25(5), 885-890. DOI: 10.1093/eurpub/ckv018
- Nelson, O. & Salawu, A. (2016). Effective Use of Media Awareness Campaigns for Breast Cancer Care Among Women: A Comparative Study, *Journal of International Women's Studies*, Vol. 17, No. 4.
- Niehoff, N., Keil, A.P., Jones, R.R., Fan, S., Gierach, G.L. & White, A.J. (2020), Outdoor air pollution and terminal duct lobular involution of the normal breast, *Breast Cancer Research*. 2020 Sep 24;22(1):100. DOI: 10.1186/s13058-020-01339-x.
- Nielsen, E. (2010). Breast Cancer Narratives, Cancer Prevention and Public Affects. *Canadian Women's Studies* 28:2.3.
- Nielsen, E. (2011). Feeling Angry: Breast Cancer Narratives, Cancer Prevention and Public Affects. *Canadian Woman Studies*. Special Issue: Women and Cancer. 28.2/3: 117-122.
- Nielsen, E. (2019). *Disrupting breast cancer narratives: Stories of Rage and Repair*. Toronto: University of Toronto Press.
- Nudelman, J., Taylor, B., Evans, N., Rizzo, J., Gray, J., Engel, C., & Walker, M. (2009). Policy and Research Recommendations Emerging from the Scientific Evidence Connecting

Environmental Factors and Breast Cancer. *International Journal Of Occupational And Environmental Health*, *15*(1), 79-101. DOI: 10.1179/oeh.2009.15.1.79

- Oed.com. (2019). *Home: Oxford English Dictionary*. [online] Available at: https://www.oed.com/ [Accessed 15 Aug. 2019].
- Ohayon, J.L., E. Nost, S. Kami, M.R. Rakoff, J.G. Brody. (2020). Barriers and opportunities for breast cancer organizations to focus on environmental health and disease prevention: a mixed-methods approach using website analyses, interviews, and focus groups. *Environmental Health*. 19:15. doi.org/10.1186/s12940-020-0570-7
- Ong, Aihwa. (2006). *Neoliberalism as exception: Mutations in citizenship and citizenry*. Duke University Press, United States of America.
- Paalosalo-Harris, K., & Skirton, H. (2016). Mixed method systematic review: the relationship between breast cancer risk perception and health-protective behaviour in women with family history of breast cancer. *Journal Of Advanced Nursing*, 73(4), 760-774. DOI: 10.1111/jan.13158
- Pan, S., Morrison, H., Gibbons, L., Zhou, J., Wen, S., DesMeules, M., & Mao, Y. (2011). Breast Cancer Risk Associated With Residential Proximity to Industrial Plants in Canada. *Journal Of Occupational And Environmental Medicine*, 53(5), 522-529. Doi: 10.1097/jom.0b013e318216d0b3
- Pedersen JE, Strandberg-Larsen K, Andersson M, Hansen J. (2020). "Breast cancer among Danish women occupationally exposed to diesel exhaust and polycyclic aromatic hydrocarbons, 1964–2016" Scand J Work Environ Health DOI:10.5271/sjweh.3923

- Petersen, A. R. (1996). Risk and the regulated self: the discourse of health promotion as politics of uncertainty <u>https://doi org.ledproxy2.uwindsor.ca/10.1177/144078339603200105</u>
- Pitts, V. (2004). Illness and Internet empowerment: writing and reading breast cancer in cyberspace, health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, Vol 8(1):33-59.
- Popay, J., Williams, G., Thomas, C., & Gatrell, T. (1998). Theorising Inequalities in Health: The Place of Lay Knowledge, *Sociology Of Health & Illness*, 20(5), 619-644. DOI: 10.1111/1467-9566.00122
- Popay, Jennie. (2003). Qualitative research and the epidemiological imagination: a vital relationship. *Gac Sanit* 17.Suppl 3 (2003): 58-63.
- Porroche-Escudero, A. (2011). *Listening to Women: Political Narratives of Breast Cancer in Spain* (Ph.D.). University of Sussex.
- Porroche-Escudero, A. (2014). Perilous equations? Empowerment and the pedagogy of fear in breast cancer awareness campaigns. *Women's Studies International Forum*, 47, 77-92.
  DOI: 10.1016/j.wsif.2014.08.003
- Porroche-Escudero, A. (2016). Empoderamiento: el santo grial de las campañas de cáncer de mama. *Revista Internacional De Sociología*, 74(2), e031. doi: 10.3989/ris.2016.74.2.031
- President's Cancer Panel. (2010). *Reducing Environmental Cancer Risk: What We Can Do Now*. https://deainfo.nci.nih.gov/advisory/pcp/annualreports/pcp08-09rpt/pcp\_report\_08-09\_508.pdf

- Prioritizing Breast Cancer Prevention. (2013). *Cancer Discovery*, *3*(4), OF3-OF3. DOI: 10.1158/2159-8290.cd-nb2013-032
- Probst-Hensch N. & Künzli, N. (2012). Commentary: Preventing noncommunicable diseases beyond lifestyle. *Epidemiology*. 2012;23:181–3
- Prodinger, B., Rudman, D.L., & Shaw, L. (2013), Institutional Ethnography: Studying the Situated Nature of Human Occupation, *Journal of Occupational Science*, pp 78-81.
- Reissman, C. (2012). Analysis of personal narratives. In J. Gubrium, J. Holstein, A. Marvasti, &
   K. McKinney (Eds.), *The SAGE handbook of interview research: The complexity of the craft.* (2nd ed., pp. 367-381). Thousand Oaks, CA: SAGE Publications, Inc. DOI: <a href="http://dx.doi.org/10.4135/9781452218403.n26">http://dx.doi.org/10.4135/9781452218403.n26</a>
- Rice, L., Brandt, H., Hardin, J., Ingram, L., & Wilson, S. (2014). Exploring Perceptions of
  Cancer Risk, Neighborhood Environmental Risks, and Health Behaviors of
  Blacks. *Journal Of Community Health*, 40(3), 419-430. DOI: 10.1007/s10900-014-99525
- Richardson, L. & St. Pierre, E. A. (2008). Writing: A Method of Inquiry. In N. K. Denzin & Y. S.
  Lincoln (Eds.), Collecting and Interpreting Qualitative Materials (3rd ed.) (pp. 473-499).
  Thousand Oaks, CA: Sage.
- Rimal, R., & Juon, H. (2010). Use of the Risk Perception Attitude Framework for Promoting Breast Cancer Prevention. *Journal Of Applied Social Psychology*, 40(2), 287-310. DOI: 10.1111/j.1559-1816.2009.00574.x

- Robertson, A. (2000). Embodying risk, embodying political rationality: Women's accounts of risks for breast cancer. *Health, Risk & Society*, 2(2), 219-235. DOI: 10.1080/713670161
- Dodson, R.E., Nishioka, M., Standley, L.J., Perovich, L.J. Brody, J.G., & Rudel, R.A., (2012),
  "Endocrine Disruptors and Asthma-Associated Chemicals in Consumer
  Products." *Environmental Health Perspectives*, 120, no. 7 (2012): 935-943.
- Rochon Ford, A., & Sweeney, E. (2015). Missing in Actions: The Critical Role of Environmental and Occupational Exposures in the Development of Breast Cancer in Women. In P.
  Armstrong & A. Pederson, *Women's Health*. Toronto: Women's Press.
- Ropeik, (2019), Why Climate Change Pundits Aren't Convincing Anyone. https://undark.org/2019/03/14/climate-change-essays-are-unconvincing-2/
- Rudel, R., & Perovich, L. (2009). Endocrine-disrupting chemicals in indoor and outdoor air. *Atmospheric Environment*, *43*(1), 170-181. DOI: 10.1016/j.atmosenv.2008.09.025
- Saw, A., Paterniti, D., Fung, L., Tsoh, J., & Tong, E. (2018). Perspectives of Chinese American smoker and nonsmoker household pairs about creating smokefree living together program. *Cancer*, 124, 1599-1606. DOI: 10.1002/cncr.31220
- Schettler, T. (2016) The Ecology of Breast Cancer with Ted Schettler, MD, MPH. <u>https://www.bcaction.org/resources/webinars/the-ecology-of-breast-cancer-with-ted-schettler-md-mph/</u>
- Schettler, Ted, (2014) "The Ecology Breast Cancer: The Promise of Prevention and the Hope for Healing," Retrieved from <u>http://sehn.org/new-release-the-ecology-of-breast-cancer-the-promise-of-prevention-and-the-hope-for-healing/</u>.

- Schreier, M. (2014). Qualitative content analysis. In U. Flick (Ed.), *The SAGE handbook of qualitative data analysis*. (pp. 170-184). London: SAGE Publications Ltd. DOI: <a href="http://dx.doi.org/10.4135/9781446282243.n12">http://dx.doi.org/10.4135/9781446282243.n12</a>
- Schwandt, T.A. (2000), "Three Epistemological Stances for Qualitative Inquiry: Constructivist, Interpretivism, Hermeneutics, and Social Constructionism." in *Handbook of Qualitative Research*, 2nd Edition, edited by Norman K. Denzin and Yvonne S.Lincoln. Thousand Oaks, CA: Sage (Pg. 189-214)

Scott, J.W. (1991), The Evidence of Experience. Critical Inquiry 17(4): pp. 773-97.

- SEER. (2019). Cancer of the Breast (Female) Cancer Stat Facts. [online] Available at: https://seer.cancer.gov/statfacts/html/breast.html [Accessed 15 Aug. 2019].
- Segal, Judy Z. (2007). Breast Cancer narratives as public rhetoric: genre itself and the maintenance of ignorance, *Linguistics and the Human Sciences*, 3-23.
- Smith, D. (1997) Comment on Hekman's "Truth and Method: Feminist Standpoint Theory Revisited" Signs, Vol. 22, No. 2 (Winter, 1997), pp. 392-398 The University of Chicago Press.
- Smith, D. (1990). Conceptual Practices of Power: A Feminist Sociology of Knowledge. University of Toronto Press, Toronto.

Smith, D. (2005). Institutional Ethnography: A Sociology for People. USA: Altamira Press.

Smith, L. T. (2007). Decolonizing Methodologies. 2nd ed. University of Otage Press, Dunedin.

- Smith, S., Nazione, S., LaPlante, C., Kotowski, M., Atkin, C., Skubisz, C., & Stohl, C. (2009).
  Topics and Sources of Memorable Breast Cancer Messages and Their Impact on
  Prevention and Detection Behaviors. *Journal Of Health Communication*, *14*(3), 293-307.
  DOI: 10.1080/10810730902805903
- Smithson, J. (2000). "Using and Analyzing Focus Groups: Limitations and Possibilities. International Journal of Social Research Methodology 3(2): 103-119.
- Solis, J. (2004). Narrating and Counternarrating Illegality as an Identity. In C. Daiute, & C. Lightfoot (Eds.), *Narrative Analysis*. (pp. 181-200). Thousand Oaks, CA: SAGE
  Publications, Inc. DOI: http://dx.doi.org/10.4135/9781412985246.n3.1
- Storey, R. (2009). From Invisibility to Equality? Women Workers and the Gendering of Workers' Compensation in Ontario, 1900–2005. *Labour / Le Travail*, 64, 75-106. Retrieved from http://www.lltjournal.ca/index.php/llt/article/view/5576
- Sweeney, E. (2014). The Individualization of Risk and Responsibility in Breast Cancer Prevention Education Campaigns. *Policy Futures In Education*, 12(7), 945-960. DOI: 10.2304/pfie.2014.12.7.945
- Tanggaard, L. (2009). The Research Interview as a Dialogical Context for the Production of Social Life and Personal Narratives. *Qualitative Inquiry*, 15, 1498-1515.
- Tarn, D., Paterniti, D., & Wenger, N. (2016). Provider Recommendations in the Face of Scientific Uncertainty: An Analysis of Audio-Recorded Discussions about Vitamin
  D. *Journal Of General Internal Medicine*, *31*(8), 909-917. DOI: 10.1007/s11606-016-3667-5

- Tavory, I and Timmermans, S. (2009). '2 Cases of Ethnography: Grounded Theory and the Extended Case Method', *Sage Qualitative Research Methods*.
- Taylor, J., and M. Patterson. (2010). Autonomy and Compliance: How Qualitative Sociologists Respond to Institutional Ethical Oversight. *Qualitative Sociology*, 1-23.
- The Collaborative on Health and the Environment. (2019). Retrieved 15 August 2019, from https://www.healthandenvironment.org/

Thomas-MacLean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social Science & Medicine*, *58*(9), 1647-1657. DOI: 10.1016/s0277-9536(03)00372-1

- Tong, R. (2006). Negotiating Personal and Political Settlements with Breast Cancer, The Voice of Breast Cancer in Medicine and Bioethics, *Philosophy and Medicine*, vol. 88
- Torre, L., Islami, F., Siegel, R., Ward, E., & Jemal, A. (2017). Global Cancer in Women: Burden and Trends. *Cancer Epidemiology Biomarkers & Prevention*, 26(4), 444-457. DOI: 10.1158/1055-9965.epi-16-0858

Van Dijk, T. A. (2006). Discourse, Context and Cognition. Discourse Studies, 8, 159-177.

- Van Tongeren, Young &. Hutchings. (2010). Occupation and Cancer in Britain, *British Journal* of Cancer 102, 1428-1437.
- Villeneuve, P., Goldberg, M., Crouse, D., To, T., Weichenthal, S., Wall, C., & Miller, A. (2018).
  Residential exposure to fine particulate matter air pollution and incident breast cancer in a cohort of Canadian women. *Environmental Epidemiology*, 2(3), e021. DOI: 10.1097/ee9.00000000000021

- Visweswaran, K. (1997). "Histories of Feminist Ethnography." *Annual Review of Anthropology* 26: 591-621.
- Vitanova, G. (2013). Narratives as zones of dialogic constructions: A Bakhtinian Approach to Data in Qualitative Research. *Critical Inquiry in Language Studies*, 10(3), 242-261.
  DOI:10.1080/15427587.2013.816827
- Volkman, J., & Silk, K. (2008). Adolescent Females and Their Mothers. *Journal Of Health Psychology*, *13*(8), 1180-1189. DOI: 10.1177/1359105308095972
- Wacquant, L. (2002). Scrutinizing the Street: Poverty, Morality, and the Pitfalls of UrbanEthnography. *American Journal Of Sociology*, *107*(6), 1468-1532. DOI: 10.1086/340461
- Walker, M.J. (2017). Corporate Ties that Bind: An Examination of Corporate Manipulation and Vested Interest in Public Health. Skyhorse Publishing, USA
- Warren & Commings, (2020). Tobacco and Lung Cancer: Risks, Trends, and Outcomes in Patients with Cancer, American Society of Clinical Oncology Educational Book , Volume 33 DOI: 10.14694/EdBook\_AM.2013.33.359 American Society of Clinical Oncology Educational Book - published online before print May 16, 2013
- White, M., Peipins, L., Watson, M., Trivers, K., Holman, D., & Rodriguez, J. (2013). Cancer
  Prevention for the Next Generation. *Journal Of Adolescent Health*, 52(5), S1-S7. DOI: 10.1016/j.jadohealth.2013.02.016
- WHO, (Date Unknown) Ottawa Charter For Health Promotion, <u>https://www.who.int/healthpromotion/conferences/previous/ottawa/en/</u> Retrieved November 2020

- Wilkinson, S. (2000). Women with Breast Cancer Talking Causes: Comparing Content,Biographical and Discursive Analyses, *Feminism and Psychology*, 2000, Vol. 10(4).
- Wilkinson, S. (2001). Breast Cancer: Feminism, Representations and Resistance a Commentary on Dorothy Broom's 'Reading Breast Cancer.' In *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*. Volume: 5 issue: 2, page(s): 269-277, Issue published: April 1, 2001, https://doi.org/10.1177/136345930100500207
- Wodak, R. (2006). 'Doing Politics': The Discursive Construction of Politics. Journal of Language & Politics, 5, 299-303.
- Wolf, F. (2010). Enlightened Eclecticism Or Hazardous Hotchpotch? Mixed Methods and Triangulation Strategies in Comparative Public Policy Research. *Journal of Mixed Methods Research*, 4, 144-167.
- Woloshin, S., Schwartz, L., Black, W., & Welch, H. (1999). Women's Perceptions of Breast Cancer Risk. *Medical Decision Making*, 19(3), 221-229. DOI: 10.1177/0272989x9901900301
- World Health Organization (2016). Preventing Disease Through Healthy Environments, Available at https://apps.who.int/iris/bitstream/handle/10665/204585/9789241565196\_eng.pdf;jsessio nid=2236E67FB5790A610E123C7052546CD0?sequence=1

- World Health Organization. (2019). Breast cancer. [online] Available at: https://www.who.int/cancer/prevention/diagnosis-screening/breast-cancer/en/ [Accessed 15 Aug. 2019].
- Wright, E.O. (2005). Approaches to Class Analysis. Cambridge, Cambridge University Press.
- Wu, S, Powers, S., Zhu, W. & Hannun, Y.A. (2016) Substantial contribution of extrinsic factors to cancer development, *Nature*, 529(7584):43-47.
- Yaghjyan, L., Arao, R., Brokamp, C., O'Meara, E., Sprague, B., Ghita, G., & Ryan, P. (2017).
  Association between air pollution and mammographic breast density in the Breast Cancer
  Surveillance Consortium. *Breast Cancer Research*, *19*(1). DOI: 10.1186/s13058-017-0828-3

## APPENDICES

## **Appendix A: Interview Guide**

The interview guide is organized to reflect the iterative process proposed in line with Kleinman's model and as such contains few questions, but numerous probes which may or may not be used in the course of any one interview. The "language" or wording of probes will be tailored to and dependent upon use the language in the answers given by the interview subjects. The main open-ended questions appear in bold, followed by areas for potential probes.

# 1. Can you tell me about yourself?

- describe life in Windsor/Essex County
- from Windsor area originally/how long here
- good things and not so good about living here
- healthy place to live or not and why
- health problems of people living here
- do you vote in elections

# 2. Where do you get your information about health?

- personally know people with problems? who?
- what they think causes of health problems are
- what they think outsiders think of health here

# 3. When I say breast cancer, what does it make you think?

- experience with breast cancer
- knowledge of breast cancer risk
- breast cancer risk and environment? work environment?
- what women at risk? what causes this risk?
- where is information about breast cancer risk coming from?

# 4. Do women have any control over breast cancer risks or are there others who might have control over risks for breast cancer?

- any or all risks
- personal level of risk for breast cancer? *Why*?
- where we live or work and risk and importance
- ways to reduce risk

# 5. Tell me about working at the Ambassador Bridge?

- environment at work
- any concerns and why
- co-workers concerns
- health impacts of workplace on community, family, self
- other perceptions of breast cancer risk for people who live near or work at the Ambassador Bridge

# 6. What do you know about the compensation case for a worker at the Ambassador Bridge with breast cancer?

- thoughts about what can or should be done
- any actions on their to reduce risks
- what options do they have i.e. remain in this job, work with union, change regulations, health movements, etc.

• what they think of studies on breast cancer and vehicle exhaust

#### **Appendix B: Media Advisory**

#### FOR IMMEDIATE RELEASE

## May 14, 2018

#### Media Advisory

#### Do Women at the Ambassador Bridge Have Distinctive Breast Cancer Stories?

**WINDSOR, ON** – Interested women workers of the Ambassador Bridge are invited to participate in an important new study underway at the University of Windsor. The study aims to gather stories from women about their perceptions of breast cancer risks.

Each week, there are 500 new diagnoses of breast cancer in Canada yet fewer than 50% of breast cancers can be explained by the known or traditionally suspected genetic and lifestyle related causes. Recently published studies suggest a contribution by extrinsic factors including air pollution and shift work. In Dr. Ted Schettler's words, "breast cancer is not only a disease of abnormal cells but also of communities that we create and live in."

"Women's stories of their breast cancer risks can give us new insights for prevention as we face the challenge before us of rising breast cancer rates" says Jane McArthur, the researcher behind the study. "Talking to women at the Ambassador Bridge might bring out stories about breast cancer that other research hasn't documented, and that possibility is exciting and intriguing!"

The central question of the research is: *How do women who work (or have worked) in an environment with an identified risk of breast cancer understand their breast cancer risks?* 

"Women's stories can tell us what matters most to these women as they confront the breast cancer epidemic in their own lives and the lives of those in their communities," according to McArthur.

Current or former Ambassador Bridge women workers who wish to participate can contact Jane McArthur to discuss the study and book their interview.

WHAT:	Study: "Investigating Women's Narratives of Breast Cancer
	Risks
WHO:	Study Participants: Any woman who has ever worked or
	currently works at the Ambassador Bridge
	Study Investigator: Jane E. McArthur, PhD Candidate,
	Sociology,
WHEN:	Beginning now through spring and summer
WHERE:	University of Windsor

\*This research has received clearance from the University of Windsor Research Ethics Board.

For further information, please contact:

Jane McArthur, PhD Candidate, Department of Sociology, Anthropology and Criminology at University of Windsor via email at <u>mcarth7@uwindsor.ca</u> or by telephone or text at **mcarth7@uwindsor.ca**. **Appendix C: Study Flyer** 

Would you like to participate in a research project?



# Title of Study: INVESTIGATING WOMEN'S NARRATIVES OF BREAST CANCER RISKS

This research study is being conducted by Jane E. McArthur, from the Department of Sociology, Anthropology and Criminology at the University of Windsor. The results of the study will be contributed to Ms. McArthur's PhD Dissertation.

If you have any questions or concerns about the research, please feel to contact Jane E. McArthur, PhD Candidate, 519-253-3000 ext. 3983 or and a structure or Dr. Eleanor Maticka-Tyndale,/*Faculty Supervisor, 519-253-3000 ext. 2200*.

PURPOSE OF THE STUDY: The research aims to investigate women's perceptions of breast cancer risks, as evidenced in their stories.

PROCEDURES: If you volunteer to participate in this study, you will be asked to: **Read** and sign the consent form provided to you, followed by a one-on-one interview with you, conducted by the study Principal Investigator, Jane E. McArthur, lasting for approximately 1 - 2 hours. You may be contacted, with your agreement, for further discussion during the course of the study. You will be provided with a summary of your interview for review. When the study is completed, you will be provided with a summary of results, if you so desire.

If you wish to participate in this study, please contact Jane McArthur, PhD Candidate, University of Windsor, via e-mail <u>mcarth7@uwindsor.ca</u> or at **definition** (telephone or text) to discuss your participation and arrange for an interview. You may also share this information with others you may think might be interested in participating. \*\*This research has received clearance from the University of Windsor Research Ethics Board.\*\*

## **Appendix D: Informed Consent**



## CONSENT TO PARTICIPATE IN RESEARCH

## Title of Study: INVESTIGATING WOMEN'S NARRATIVES OF BREAST CANCER RISKS

You are asked to participate in a research study conducted by Jane E. McArthur, from the Department of Sociology, Anthropology ad Criminology at the University of Windsor. The results will contribute to Ms. McArthur's PhD Dissertation.

If you have any questions or concerns about the research, please feel to contact Dr. Eleanor Maticka-Tyndale, *Faculty Supervisor at 519-253-3000 ext. 2200 or* Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: <u>ethics@uwindsor.ca</u>

#### PURPOSE OF THE STUDY

The purpose of the study is to gain a better understanding of women's knowledge of breast cancer risks and what actions might be seen as important to mitigate these risks.

#### PROCEDURES

If you volunteer to participate in this study, you will be asked to:

(1) Read a consent form and decide whether to participate in the project and. (2) If you agree to participate you will engage in a 1-2 hour interview with Jane E. McArthur (3) If you agree, you may be contacted for further discussion during the course of the study. Soon after your interview has been completed, you will receive a summary for review and will have two weeks to provide final approval for its inclusion in the study or, alternatively, to withdraw your interview from the project. When the study is completed, you will be provided with a summary of results.

#### POTENTIAL RISKS AND DISCOMFORTS

Some participants may feel some emotional discomfort around the issue of breast cancer or health generally, during or after the interview. A list of resources will be provided should you feel the need to address your discomfort or concerns.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY Benefits to participation include being able to share your knowledge, experiences and insights about how you understand breast cancer risks and potential actions. In addition, your participation in this research may help improve our knowledge of breast cancer risks and may lead to changes in risk mitigation strategies for women like you.

#### COMPENSATION FOR PARTICIPATION

Your parking costs for coming to this meeting will be covered and if you agree to participate in the interview you will be given a \$25 honorarium.

## CONFIDENTIALITY

Your decision about participation in this study and any information that is obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission.

Efforts to maintain confidentiality include: using a pseudonym in reporting your contributions to the study (you may select your own pseudonym); keeping your name and other identifiers separate from the interview transcripts and destroying this information as soon as contact with you is no longer necessary; retaining scanned copies of consent forms on a password protected computer and storage drive with hard copies shredded; and procedures to insure recordings and relevant documents are available only to the researcher (Jane McArthur) and her supervisor (Eleanor Maticka-Tyndale). Procedures related to recordings and documents include: uploading and retaining audio recordings on a password protected computer in a secure location; erasing interviews from the audio recorder as soon as uploading is confirmed; transcribing and retaining transcripts and notes related to interviews on password protected computers on password protected computers on password protected computers and files and erasing audio-recordings once accuracy of transcripts has been verified. Transcripts will be kept for 10 years on a password protected storage drive.

Despite these precautions, it is likely that you will be able to identify yourself based on quotations from your interview (especially if you choose the pseudonym to be used). In addition, other participants who know you may be able to identify you (and you identify others whom you know).

## PARTICIPATION AND WITHDRAWAL

Participation in this research is completely voluntary. You may choose not to answer any questions that are asked of you and you may choose to end your interview at any time. If the interviewer feels that you are experiencing distress during the discussion, she will end the interview and provide you with information about where you can receive assistance or counselling to help deal with your distress. The interviewer may withdraw you from this research if circumstances arise which warrant doing so. When your interview has been completed, you will be provided with a summary of your interview for review soon after and will have two weeks to provide approval for inclusion of your interview in the study or you may withdraw from the study at this point. This is the last point at which you may withdraw from the study.

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

Results of the study will be provided to you should you so desire in the form of a 1-2 page summary. When the dissertation is complete, you will be welcome to access it to read the completed dissertation. Any public meetings or events which may result from this study will be open to you to attend.

### SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, in publications and in presentations.

### RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: <u>ethics@uwindsor.ca</u>

SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE I understand the information provided for the study Investigating Women's Narratives of Breast Cancer Risks as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

I agree to allow Jane McArthur, the researcher, to use a digital recorder to record my interview for the purposes of accuracy.

Name of Participant

Signature of Participant

Date

These are the terms under which I will conduct research.

Signature of Investigator

Date

\*\*This research has received clearance from the University of Windsor Research Ethics Board.\*\*

## **Appendix E: Interview Summary Template and Ongoing Consent**

This summary provides an overview of the key points you shared in your interview. It does not include everything discussed, but rather is a summary of the main themes related to the study questions and overall shared themes as they came up in the course of all of the interviews. The information included here and as planned for the dissertation is in keeping with trying to maintain your anonymity and confidentiality. Please feel free to add information where it is missing below.

ID #	
Pseudonym	
Age	
Residences	
Position at Bridge	
Length of Time at Bridge & Employment Status	
Education	
Breast Cancer Diagnosis	
Causes of Breast Cancer Mentioned	
Information Sources	
Aware of Compensation Case	
Knowledge of Bridge workers breast cancers	
Other health problems mentioned	

You told me that you live...

When we talked about where you get information about health you told me...

You talked to me about your own experiences...

When we talked about whether or not women have any control over their risks for breast cancer ....

When we talked about working at the Ambassador Bridge ... Prevalent themes in your story included...

Some notable quotes from your interview include: "...

Thank you again for your participation in the study.

As agreed to at the time of your interview, you are being provided with a summary of your interview for review and have two weeks to provide approval for inclusion of your interview in the study or you may opt to withdraw at this point. If I have not received word from you in one form or another, I will assume consent for ongoing inclusion in the study.

You may sign this form and return it, or you may e-mail or call Jane McArthur to acknowledge receipt of the summary and confirm your participation.

## SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I acknowledge receipt of the information summary of my interview for the study Investigating Women's Narratives of Breast Cancer Risks as described herein. I agree to the information from my interview being included in this study.

**Name of Participant** 

**Signature of Participant** 

Date

Jane McArthur can be reached at mcarth7@uwindsor.ca or

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: <u>ethics@uwindsor.ca</u>

# VITA AUCTORIS

NAME:	Jane E. McArthur
PLACE OF BIRTH:	Windsor, ON, Canada
YEAR OF BIRTH:	1972
EDUCATION:	Walkerville Collegiate Institute, Windsor, ON,
	1991
	University of Windsor, B.A., Honours
	Communication Studies, Windsor, ON, 1998
	University of Windsor, M.A., Communication
	and Social Justice, Windsor, ON, 2014