Living⇔Dying with Metastatic Breast Cancer: Women's Accounts of Living Longer in Smaller Communities

by

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M.S.W., University of British Columbia, 2008

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Supervisory Committee

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Abstract

As a life-limiting illness mediated by rapid advancements in biomedical technologies, metastatic breast cancer (MBC) now presents in increasingly unexpected ways where women are living longer. These women's lives may not fit well with established healthcare and societal understandings of an advanced breast cancer, including disease progression and prognosis. This qualitative inquiry aims to think differently about women's daily lives with an ongoing MBC. While also considering the underexplored context of these women living in smaller communities. I explored communities on Central Vancouver Island, which is on the west coast of British Columbia, Canada. The research question directing my inquiry was: how are women, who are living with MBC as a life-limiting illness over an extended period, produced as both living and dying subjects? Informing this research was a feminist relational materialist approach with a healthcare practitioner orientation, primarily informed by Braidotti. I used multiple data collection methods centred around sequential interviews with 14 women who had been living relatively well with MBC for at least two years.

Working with relational materialist and post qualitative principles, analysis disclosed the importance of *temporal pulses* and *bodily transpositions* in women's lives. Temporal pulses speak to how time was laden with tensions such that a distinctive part of living with ongoing MBC was an embodied sense of fluctuating time. There was also the idea as to how, at any given moment, women could bodily know their illness and mortality through varying frequencies of the presence and/or absence of markers of living and dying, often at the same time. Bodily transpositions speak to how life-limiting illness was not so much about women moving from one set of circumstances to another as part of a clean-edged transition. Rather, the women navigated daily life with few set waymarkers. Within this context, 'hope' took on new forms and living with their advanced breast cancer became a kind of endurance demarcated by what I refer to as generative living.

These findings call into question the ways in which MBC gets talked about in categorical terms as palliative or end of life, and/or as chronic. Findings are an opportunity for healthcare practitioners, policymakers, and interdisciplinary leaders to further understand MBC specific to our contemporary context. Project findings renew discussions of how best to support women's needs, including the ways MBC is talked about. There is also the opportunity to direct further research into MBC as an example of today's shifting boundaries of living and dying (which I am framing as living⇔dying).

Keywords: Braidotti, living and dying with advanced cancer, living longer with life-limiting illness, metastatic breast cancer, post qualitative inquiry, feminist relational materialism, women's health in smaller communities

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Acknowledgments

Doctoral work is like a pilgrimage of old. It is work that is about taking many steps while learning to be comfortable with where you are because you have come to know that you are not entirely certain where you are going. Moreover you meet many people along the way who end up becoming a part of that pilgrimage, people for whom you are most thankful for. Doctoral work carried out over an extended period because of illness is such a pilgrimage yet characterized by inhospitable weather and wrong supplies. The number of people you are thankful for grows, and the depth of that thanks is often something that can be too heartfelt to adequately put into words. The acknowledgments shared here are only stone markers along the road, while the depth of my gratitude is more like the expanse of the surrounding fields and sky.

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To my colleagues at Island Health, who have been with me all the way: Thank you for your encouragement and enthusiasm.

Dedication

Hic sunt dracones ...

To Marion Shermak, the dragon boater whose cancer advocacy is a ‘master-stroke’

To Constance Barker, the pilgrim who had little fear of uncharted territories

To Barbara Fisk, the lady of dragons who in her roar was a heart song,

if you listened

And to Peggy Morrison, the lifelong learner who took flight despite barriers

Chapter 1: An Entry Point Into Living⇔Dying

> These are the days of miracle and wonder … medicine is magical and magical is art … the boy in the bubble. And the baby with the baboon heart.
>
> — fragments of Patti Smith's 2007 performance of "Boy in the Bubble" (Simon & Molloheloa, 1986)

The purpose of this first chapter is to situate the dissertation as a space for thinking differently about what it is for women to be living with metastatic breast cancer (MBC) in our contemporary times. This dissertation, therefore, reflects an exercise in thinking critically about the shifting boundaries of living and dying, I will, hereinafter, refer to living and dying as living⇔dying. MBC is one of the advanced cancers where living is etched with a precarious uncertainty of life and dying is removed from progressive-decline toward death. There is an indeterminacy of living and dying, where women dwell in "the land of living/dying" (Nissim et al., 2012, p. 360). With an ongoing form of MBC, women are neither marked with death nor assured of a cure. I developed my project in response to what breast cancer survivorship has become in the past twenty years, and the silences that persist around a life-limiting illness still often associated with death, yet one that may be changing. I also aim to provide practitioners with an understanding of an advanced cancer that resonates with their practices, particularly with the realities of emerging disease trajectories given technological advancements (Broom, Kenny, & Kirby, 2018). The overall research purpose is to contribute to a more nuanced understanding of women's embodied and embedded lives as they are living⇔dying with MBC.

In this introductory chapter there are three sections that are an entry point into living⇔dying. First, I introduce MBC via the debate of how long women can live with this life-limiting illness. Second, I discuss how drawing on work by philosopher and feminist theoretician Rosi Braidotti provides insight into thinking differently about MBC and living⇔dying in contemporary times. Third, I discuss how within her wider philosophical project, Braidotti's relational materialist approach can support my practical inquiry into living⇔dying with MBC.

Introducing MBC: How Long Can Women Live with this Life-Limiting Illness?

In addition to biomedical descriptions, MBC has a multi-faceted social profile that provides glimpses into the impact of MBC in women's lives. From both personal and professional encounters, I am aware that MBC is not one entity but can be many things. It is a type of cancer. It is a stage of breast cancer. It is a 'failure' of normative breast cancer survivorship, or now in a growing number of cases, a 'revival' of survivorship. It is a cluster of advanced breast cancer subtypes. It is, in some forms, a fit with the designation of chronic illness. It is a life-limiting illness where the natural history of the illness is increasingly mediated and transformed by biomedicine. It is a palliative health condition. With such a range of things that it is, MBC plays out differently for each person.

A pragmatic starting point for a discussion about MBC today is to talk about how long women typically live with the disease. Talking about survival rates is important in a life-limiting illness because it provides a temporal limit to the illness. Yet, the talk about survival rates does not resonate with the statistics available for MBC since most statistics are not well-established. They can be inadequate or lacking altogether (Willis, Lewis, Ng, &

Wilson, 2015). Statistics are not always specific to MBC, nor do they necessarily separate MBC from other types of breast cancer. Not differentiating types of breast cancer can be problematic because survival rates are not the same across all breast cancer types and across stages of cancer (Helwick, 2015).

I undertook my research on Central Vancouver Island, British Columbia, Canada. The statistics reported here that inform survival rates, come from the British Columbia (BC) Cancer Agency metastatic breast cancer guidelines (2017). The median survival for MBC in British Columbia is 24 months. However, the BC Cancer Agency (2017) now tempers this finding by adding that there is a wide temporal range of survival, ranging from "several months in extreme cases, to 5 or more years" (6.93 Prognosis section, para. 1). There is also "a small but significant fraction of patients achieves [*sic*] long-term disease control and survives more than 10 years" (6.93 Prognosis section, para. 1). These statistics represented a change since the start of my research project in 2009 when there was far less understanding that MBC might be changing and there might be different illness trajectories resulting in living longer with MBC.

Discussion about whether women are living longer with MBC, and if so, what their lives are like, has recently expanded from a limited place within only a few corners of the cancer community to a debate threaded across diverse sites and disciplines. This growing interest in MBC has arisen because significant advancements in clinical therapeutics are producing new types and presentations of cancer (Thorne, Oliffe, Oglov, & Gelmon, 2013), including recent medical advancements for treating advanced breast cancer. The development of screening and treatment objectives in the late 20th century first expanded primary breast cancer disease, both spatially and temporally (Klawiter, 2008).

In thinking about how long women might live with MBC, there has also been recent debate as to whether MBC might be one of the life-limiting illnesses that could be considered a ‘chronic illness.’ Bern-Klug (2004), a social work theorist, documented how the time known as ‘end-of-life’ has shifted dramatically since the beginning of the 20th century and physical death now often occurs within the context of a chronic, not an acute illness. Ours is a time of ambiguous dying with unclear outcomes (Lynn, 2005). Joining the classic example of HIV/AIDS, there are advanced cancers that have been discussed as possibly being chronic illnesses (e.g., Harley, Pini, Kenyon, Daffu-O’Reilly, & Velikova, 2016), including MBC (e.g., Zuzelo, 2019).

There is a need in healthcare for greater recognition of ambiguities arising from living with serious illness and pathways to dying today. A lack of recognition is to exclude a growing group of people who have life-limiting illnesses (Lage & Crombet, 2011; Reed & Corner, 2013). This lack of recognition can mean there are healthcare system gaps in client care specific to those illness presentations. The debate over whether MBC is an ongoing illness is an emerging and contested topic within biomedical circles. It is directly linked with advancements in breast cancer screening and therapeutics. Across Canada and in British Columbia, there is no consensus as to whether MBC should be given the status of a chronic illness.

Thinking Differently about MBC: Drawing from Braidotti’s Critical Posthumanism

To address the contemporary landscape of life-limiting illness and the trend of new lives being possible for those who have advanced cancer, I find inspiration in the critical posthuman approach of Rosi Braidotti. Braidotti’s (2010a) is an approach attuned to the "shifting boundaries between life and death" (p. 201) in today's milieu and is pragmatic because she intends it for practitioner-driven inquiry, not merely philosophical inquiry. Braidotti's approach is a way to engage generative thinking on MBC that I then apply in this dissertation project.

As a scholar in the critical humanities, in the Netherlands, Braidotti has put together a body of work that focuses on generative potentialities of posthuman theorizing for addressing contemporary social issues. Her approach is gaining favour among those interested in critical analysis across the social sciences and professional disciplines. *Posthuman* refers to our time in history, which is characterized by "intense technological mediation" (Braidotti, 2013, p. 9). Because we are all heavily implicated with the technologies that saturate our daily lives, it is vital to address the rapidly shifting concerns around humanity (Braidotti, 2017). Braidotti herself is a leader in this intellectual moment, offering a critical brand of posthumanism defined by a particular politics and ethics. Hers is a radically compassionate approach. Steadfastly connected to a caring concern for real-life conditions and life's everyday struggles, her unique theoretical approach affirms a commitment to the present (Braidotti, 2015). For Braidotti (2016) the present is not only about the time of here and now. It is also about what we are in the process of becoming and what we are seizing to be.

Braidotti's (2013) focus is on dynamic forces of our technologically-mediated time where "the boundaries between the categories of the natural and the cultural have been displaced and to a large extent blurred by the effects of scientific and technological advances" (p. 3). Thus, she discusses the need for new forms of critique and activism, because issues of human enhancement are so often at the core of social debates.

Addressing this need, she troubles a clear-cut distinction between nature and culture by advocating a nature-culture *continuum*, where nature and culture are not distinguishable parts of a binary. She argues this reimagining is central to addressing our posthuman condition, given both the speed and the intensity of the technological shifts woven into the fabric of our current society. Our world is one where engaging the relationality of nature-culture is ever more beneficial. Thus, the focus on the relationality between nature and culture is part of Braidotti's commitment to shake apart restrictive dialogues revolving on the axis of either/or by applying the productive action of 'and, and, and.' Such posthuman thinking is, in part, a renewed concern with the materialities of everyday living. It is an engagement with new ways for bringing matter and materiality into scholarship.

Explicitly developed to be an approach that is up to the challenge of our particular time in history, Braidotti (2017) describes her critical posthumanism approach as a convergence of anti-humanism and postanthropocentricism. Anti-humanism posits 'human' as a construct that is not neutral, which is in direct contradiction to the humanist claim of a universal subject. Anti-humanism brings to the fore subjects that have been subjugated to Enlightenment-era propositions, including: rationality, masculinity, and able-bodiedness. It is inclusive of knowing subjects considered less than fully human within knowledge systems steeped in humanism. Beyond consideration of human subjects, anti-humanism includes non-human beings, non-human things, and inanimate things. Concomitant with Braidotti's anti-humanism is a specific type of postanthropocentricism. Braidotti understands postanthropocentricism as a practice of enlivened engagement with a world that is conceptualized as far more than merely, or only, human. A world in which agency is not possessed by individuals but "is understood as attributable to a complex network of human and nonhuman agents, including historically specific sets of material conditions that exceed the traditional notion of the individual" (Barad, as cited in Jackson & Mazzei, 2012, p. 114). A "postanthropocentric approach allows for a nonbinary way of positing the relationship between same and other, between different categories of living beings, and ultimately between life and death" (Braidotti, 2011b, p. 328). The widening of what counts as a subject and the recalibration of human-based agency, means the posthuman embraces a generative empathy for life in its many and complex permutations. Braidotti (2013) further steps outside of strict adherence to social constructivism with her concern for "the non-human [as] vital forces of Life, which is what I have coded as *zoe*" (p. 60). Humans are *part of* vibrant materialities within a profoundly real-world or Life, allowing for thinking beyond constructs of "death" and/or "life" and into the messy intricacies of living⇔dying. These twin pillars infuse Braidotti's critical posthuman approach and position it as a systematic rethinking of how life is being lived at this point in history.

Braidotti provides a polyvocal approach, one that acts both as a tool for navigating posthuman complexity and as part of a commitment for the generation of multiple and complex subjects. The sources described here are particularly salient in informing how Braidotti thinks. She draws heavily on other philosophers' work, including Baruch Spinoza's monism, Michel Foucault's rendering of the subject, and Gilles Deleuze's approach to thinking. A key proposition she draws from a Spinozist monism is the relocation of difference from a focus on dialectics or polarities, as is the case with humanism, to a focus on degrees, or modulations, of difference. The *monistic universe* is one where "matter, the world and humans are not dualistic entities structured according to principles of internal or external opposition" (Braidotti, 2013, p. 56). Thus, from Spinoza, she finds the impetus for a need to deal with the complexities of a posthuman life where the subject is regularly uncertain and paradoxically positioned. Like Foucault, she emphasizes the relationality of subject formation. She details how systems of power in society have shifted in focus away from being one of a disciplinary nature toward being one of control (Braidotti, 2011b). Foucault studied modes in western culture thought, through which subjects form. Crucial to understanding subject formation is his rendering of power relations in which subjects are embedded in a world where power is not localized to one source. Nor is power something one holds. Referencing Foucault, Braidotti points out, "power is a situation or a process, not an object or an essence. Subjectivity is the effect of these constant flows of in-between power connections" (Braidotti, 2011b, p. 4). Imbuing Braidotti's critical approach to subjectivity is her Foucauldian concern for forces that restrict or oppress (*potestas*) and for affirmative or empowering forces that open up possibilities for what people can be (*potentia*). Not discrete from either Spinoza or Foucault, Braidotti looks toward Deleuze, her mentor, for a process of critical thinking that defies the disembodiments and the foreclosures of humanist thought. Often working with Félix Guattari, Deleuze's (1995) project was one of constructing "intellectually mobile concepts" (p. 122). Concepts that can move from one context to another or can capture the intensity of a phenomenon in a single place. The resulting mobility, when mapped, resembles a rhizome. Braidotti relies on thinking like a rhizome as the basis for her analytical approach. Through a "rhizomatic complex" she is able to weave her distinct nomadism. This is a nimble, non-reductive approach to philosophical thought that "instills movement and mobility [into] the heart of thinking" (Braidotti, 2011b, p. 1). Of note to the posthuman project and my interest in it, is her engagement with Deleuze's vitalism. She has an ontological focus on a world that is understood as densely material and as enlivened, imbued with dynamic forces of life. For Braidotti, vitalism is a way to chart a course through a world that is complex precisely because of the impersonal forces sustaining a kind of relationality exceeding easy thought.

Placing Braidotti's Wider Philosophical Project into a Practical Inquiry

Within Braidotti's critical posthumanism, it is from her relational materialist work that I will draw ideas for my project. Braidotti is a self-proclaimed 'feminist materialist.' She positions her thinking within a neo-materialist framework for understanding the world. Her overall project is part of the material turn in feminism. Her materiality-oriented work intersects with other feminist works of the material turn, including Karen Barad (2007, 2008), Stacy Alaimo (2008, 2012), and Nancy Tuana (2008). In Braidotti's approach, she maintains her political commitment as a feminist and shows how matter-realism situates bodies within the world. She sets up inquiry as an exploration of the *entanglement* of the material (matter, the nitty-gritty of everyday life) and the discursive (ideas, thinking). Entanglement is a key term that emphasizes how discourse and matter are not discrete forces playing off each other. Discourse and matter are relational. Thinking in terms of how a rhizomatic complex is entangled with discursive notions of MBC and the materiality of living⇔dying with MBC shows the non-binary nature of, for example, subject formation. As part of my project, I have had to think through what place a feminist materialist theory, arising from deep within the heart of European humanities, might have in a research endeavour that seeks to understand the formation of a living⇔dying subject among women with MBC living in the central part of Vancouver Island in British Columbia, Canada.

Following Braidotti, my inquiry does not privilege either discourse or materiality. Similarly I want to focus on the ebb and flow of how humans, non-human living things, and inanimate things are discursive and material at the same time. Braidotti's (2006) feminism draws on a brand of embodied materialism that seeks to be "thinking through the body, not in flight from it" (p. 216). The body is more than flesh and bone; it is part of an array of materialities in a social world. In inquiry or research, the body is not an empirical unit or a surface for observation. The body is a terrain of forces in need of critical engagement. In my research, I want to see how these forces that resonate through women's bodies can show what living⇔dying may be. Braidotti's (2013) approach holds a vitalist focus on living matter, one distinguished by having no "overarching concept of life, just practices and flows of becoming, complex assemblages and heterogeneous relations." (p. 171). I want to hold this vitalist idea of living, of *zoe,* in my analysis to keep the women's lives central to the project. In practical terms. I am interested in the concrete practices that generate life as we know it.

I understand Braidotti's approach as having much to offer in terms of generative critical thinking about shifting landscapes of today's life-limiting illnesses. For instance, this approach is an analytical pathway not restricted to parameters set by biomedical framings and propositions. Nor is it restricted by sets of statistics collected to determine the length of life through survival rates. However, my dissertation research project, like any project about MBC, cannot be cleaved neatly or entirely from healthcare and the medical realm. In particular, my situatedness in medical social work. As a researcher and social worker, I have an ethical commitment of accountability to the women who came forward to participate in this project and the contributions to healthcare conversations about client support.

In answer to my question about what a critical feminist materialist theory from European critical humanities can offer a research endeavour like mine, it is that Braidotti's is a "practical philosophy" (Braidotti, 2016). Her approach has a well-developed ethical attunement for real-life conditions, because it is crafted for pragmatic application in real-world settings. Braidotti's work is both embedded *and* embodied. By embedded, I mean that it is not a 'theory from nowhere' but always situated in some context. Questions for analysis arise from within particulars of the everyday. By embodied, I mean the subject is never rendered as an individual who can be objectively observed. The subject exists within an enlivened world of materialities characterized by relationships and not disconnections. A rendering of embodiment where the 'self' is not fixed to the notion of the individual. Instead, it is understood as a complex web of social relations and as one energy in a tangled mass of relationships.

Braidotti's approach permits a deeply empirical inquiry, grounded in the registers and complexities of the day-to-day world. Here the world is framed as ever-unfolding. It is neither precast nor static, one awaiting discovery. From this world arises an affirmative politics, which is a sustainable, ethical way to live and honour life. Flowing from this politics, Braidotti appeals for staying with the impersonal, relenting forces of Life that exceed the quantification of experience (Braidotti, 2017). For this project, I seek to stay *with* the vital tension around the idea that we do not know what bodies can do (Braidotti, 2013) — a recurring theme in Braidotti's relational materialist thinking. My goal is to think about how bodies are more than simply matter. For example, using her approach, it is possible to think directly about how the biomedical parameters of metastatic breast cancer are the most porous and tentative of boundaries, as embodiment exceeds such human constructions. What this may mean in real life is that the doctor tells a woman she is dying each visit, yet sees her three times a year over a ten-year period. Such thinking is towards "adequate expression of what bodies — as both embodied and embrained [these terms are part of a project to reject mind-body dualism] — can do and think and enact" (Braidotti, 2018, p. 21). Her type of generative pragmatism creates space in analysis for the vital forces of life beyond the human-centric concern of lifespan, while refusing to lose sight of life in an anthropocentric society (Braidotti, 2016). Overall, hers is an approach that is constructed to actualize abstract theorizing into an applied form of activism.

My research focuses on a particular life-limiting illness, yet I still want to focus on human beings and human concerns, as outlined in Braidotti's practical philosophy. Helping to explain how an inquiry informed by critical posthumanism, like mine, may focus on human subjects. Braidotti herself encourages activism-oriented practitioners to put her theory to work, and it is the practices of these posthuman-informed practitioners that bring to life her claims. Posthuman-informed practitioners work in the margins of diverse fields, from teaching and law to filmmaking and social work. They all have practices driven by dynamic feminist and social justice commitments. Braidotti's critical brand of posthumanism inherently holds concern for different degrees of human in this historical moment, for different registers of becoming in a world of materialities. Thus, one direction for posthuman-informed practitioners is to foreground subjects with *real* bodies living in *real* time. We need to explore intensities such as pain, mortality, and social invisibility.

Intensities such as these are both open questions and ethical concerns with MBC as an ongoing life-limiting illness and women's needs in the everyday. Braidotti's approach, her particular brand of posthumanism, is indeed applicable to my inquiry of women living longer with MBC as living⇔dying subjects.

Conclusion

In this chapter, I have offered an entry point into thinking about women's lives with MBC as an example of living⇔dying. I began this chapter with an introduction to MBC by way of the contemporary debate on how long women can live with MBC. I then reviewed Braidotti's critical brand of posthuman feminism as a lens for exploring MBC as a life-limiting illness in transition because of contemporary technologies.

This introductory chapter opens the dissertation by exploring the intersection of MBC and Braidottian theory. I have shown that I can turn to Braidotti's relational materialist approach because it offers a way to think differently about the contemporary manifestations of MBC. I will build on this throughout the dissertation.

In the next chapter, I provide an overview of how MBC is being discussed today. I identify how to enter into a critique of these discussions and then show how these discussions inform my conceptualization of the dissertation research project. This includes discussion of the research question and objectives. I follow this with a theory chapter where I set out the feminist relational materialist equivalent of a theoretical framework for my project. In the methodological considerations and research design chapter I show how I can use the approach to frame my analysis as one grounded in the day-to-day that has had practitioners in mind in its development. I follow this with two chapters of findings. I conclude the dissertation with key theoretical, methodological, and empirical insights from this project. In that final chapter I also offer potential implications for healthcare practice and possible directions for future research.

Chapter 2: The Language of Metastatic Breast Cancer and Working to Think Differently

> A rather complex relationship to death has emerged in the technologically mediated universe we inhabit; one in which the link between the flesh and the machine is symbiotic and therefore establishes a bond of mutual dependence.
>
> — Rosi Braidotti (2007, p. 19)

One of my aims in this inquiry is to think differently about women's lives with metastatic breast cancer (MBC). I am focusing on women in smaller communities living with forms of ongoing MBC that are examples of contemporary life-limiting illnesses. I refer to these forms as living⇔dying with MBC because these women live within the uncertainty of shifting boundaries of how living and dying shape their day-to-day. The women I spoke with for this project lived on Central Vancouver Island in British Columbia, Canada. Central Vancouver Island is part of the Global North, where rapid and multiple technological advancements are transforming the boundaries of living and dying. Ongoing MBC is more a disease of life limits than of life threats, and thus is drawing considerable attention within healthcare. For example, in some areas, how to provide healthcare to women living longer with advanced cancer. Within the context of how MBC is changing, for my project about living⇔dying, I have found that a critical relational materialist framework is an effective means for inquiry. This framework has led me to consider how language sets up thinking about MBC in particular ways, including for the women with MBC who are living⇔dying.

In this chapter, I situate MBC among the various ways it is spoken about as a life-limiting illness. I begin with a disclosure of how I came to the topic of this inquiry. This kind of disclosure is a starting point for empirical inquiry informed by the philosophy of Rosi Braidotti. I then organize my discussion around the themes of key characteristics that delineate MBC in healthcare, how biomedicine typically frames MBC, and language I have chosen to use in this project. I close with a discussion about how I am positioning MBC for this project.

What is it I have Forgotten to Forget?: How this Project Came to be

Part of a relational materialist approach is to critically explore the reason one has chosen their topic to research. Building on her earlier theorizing yet going in a new direction, during a lecture for advanced students, Braidotti insisted that for those of us embarking on an empirical inquiry, we needed to consider "what is it you have forgotten to forget?" (personal communication, August 21, 2017). If you do not know what is propelling you to take on a project in the first place, then assumptions about the topic will seep into your work unchecked. She continued by saying that to engage that question better, ask yourself, "what damages are you repairing?" (Braidotti, personal communication, August 21, 2017). 'Forgotten to forget' as applied in empirical inquiry, shares roots with the longstanding themes in Braidotti's work of "a practice of accountability" through "one's embodied and embedded locations" (Braidotti, 2010b, p. 410) and tracing "the traumatic impact of painful events" (Braidotti, 2011b, p. 289).

To satisfy this starting place for inquiry, I turned to the many encounters with MBC I have had in both my personal and my professional life (see Appendix A for details). For example, I am a medical social worker specialized in psychosocial oncology, a breast cancer advocate, and a person who has been a family caregiver or companion for more than one loved one with MBC. I have a deep and embodied knowing of what it is to live day-to-day with breast cancer, and I am aware of shifts in its status as a life-limiting illness over the past two decades. Further, as smaller communities are my geographical context for paid work and my long-time residence, I have an awareness of what it is to mediate wellness with breast cancer in such communities.

As early as the late 2000s, I started to observe how women's lives with advanced breast cancer were changing. There were many signs that MBC was not the disease we in breast cancer culture once knew, one strictly understood as a 'killer.' For example in 2009 at the start of my doctoral degree, there were tentative discussions of MBC as being non-palliative. However, such discussion was uncommon and differed by region, practitioner, community members, and healthcare practice sites. More dominant were the emerging healthcare debates on a changing landscape of life-limiting illness. Debates shaping the ways life-limiting illnesses were being framed in smaller communities on Vancouver Island. There were also indicators of how an array of biomedical advancements played a role in the shift I was convinced was occurring.

My encounters in diverse contexts with MBC and living⇔dying led me to explore possible research topics. For example, I reviewed palliative care for breast cancer and MBC specifically. After review of the literature, I focused my inquiry on women in smaller communities who were mediating MBC as a serious illness that they could not have anticipated would become ongoing, including over a span of many months or years. I thought of women living with MBC as being within a landscape of many and rapidly changing biomedical advancements that may permeate living with MBC long-term. A landscape that is posthuman (see Chapter 1). A day-to-day Braidotti would think of as posthuman. I also considered smaller communities as characterized by social realities where women can be relatively socially isolated and where few people, outside the experience of advanced cancer, know about it.

The research question guiding my inquiry is: how are women, who are living with MBC as a life-limiting illness over an extended period, produced as both living and dying subjects?

a) How do permutations of uncertainty contribute to the materialization of these women as subjects who are both living and dying simultaneously?
b) How do women with an ongoing form of MBC mediate the resources available to them in their everyday lives?

MBC as Defined in Healthcare

To provide a workable definition of what MBC is, I begin with three ways it tends to be delineated in healthcare practice: MBC is an illness that has spread; MBC is an illness diverse in its presentation, and MBC is an illness difficult to prognosticate. I draw these characteristics from my literature review and my practice experience. Each of these characteristics supports thinking about the intersection of women's daily life with MBC and medical science.

An Illness that has Spread

Within medicine, cancer is a disease delineated by stages. The level of cancer involvement in the body marks each stage. Cancer stages range from 0 to 4. Stages are primarily determined by the size and growth of the cancer, with stage 0 as the lowest level of cancer involvement in a body. Until very recently, stage 1 had been the lowest level. However, molecular science is allowing for new insights into identifying cancer at even earlier stages. Stage 4 is the most advanced level of involvement, with the least desirable outcomes. According to the British Columbia Cancer Agency (2014) stage 4 breast cancer is where "the breast cancer has spread beyond the breast area and lymph nodes to another area (for example bone or liver)" (Breast Cancer Stages section, para. 2). Such spread is referred to as metastasization. The most common site of MBC progression is in bone matter, and bone treatment is a common MBC therapeutic. When the progression of breast cancer is primarily limited to bones, there is less threat to life than when the cancer has spread to organs and/or soft tissues.

An Illness Diverse in Presentation

MBC is an unpredictable biological condition not deeply understood within spheres of clinical medicine (Warren, 2010). There is the literature I draw upon, however, because mine is a practitioner relational materialist inquiry, for this subsection I want to draw primarily on practitioners in the field. A former oncologist on Vancouver Island, whom I know from my own practice and who asked me not to share her name, told me that after having worked in the area of breast cancer for decades, she still did not have a conclusive understanding of it. She said MBC presents in so many different ways, just as so many variables influence it. The doctor had come to believe that she had no control over who would live and who would die from breast cancer. Likewise, Vancouver's Dr. Karen Gelmon (who in our conversation agreed to be identified in this dissertation, personal communication, September 10, 2018), a respected physician who is an expert on MBC and a key informant for this project, is adamant that MBC is a highly variant cancer. So much so, she cautioned about speaking singularly of metastatic breast cancer. She discussed how each woman, has a unique combination of factors influencing how the illness manifests and how it progresses. Later in this chapter, I discuss heterogeneity as a key factor in the unknowability of breast cancer and how it is coming to characterize contemporary understandings of MBC.

An Illness Difficult to Prognosticate

In some clinical practice circles, breast cancer has been defined by its randomness when compared to other cancers. Thus, just as in the presentation of advanced breast cancers, there are complexities in prognostication. Since the mid-1980s, significant medical advancements in breast cancer have provided useful insights into disease processes. However, in some ways, these insights have compounded the characteristic of the unknowability of MBC as a disease. Most notably is the interplay between novel therapeutics and prognosis at times of both diagnosis and afterwards. There are biological clues at the time of diagnosis, but a definitive prognosis for most subtypes is often out of reach unless a client presents with markedly advanced disease. Also, with MBC, different clinicians, given their training and/or practice experience, can have widely different prognostication practices. MBC prognoses, if provided, can either provide some sort of a sense of how much time to expect or, more typically, can be highly open-ended in nature and not be of much use to individuals.

Discussions of MBC Disease in Biomedicine

In modern Western scientific medicine, MBC is typically discussed as an advanced breast cancer, a leading cause of cancer death, and an incurable illness. There is agreement across different statistical sources, countries, and disciplines that in developed countries, breast cancer is the most common or prevalent cancer among women worldwide (e.g., Lewis, Willis, Yee, & Kilbreath, 2016; Lim & Hortobagyi, 2016). When talk emphasizes that there is no cure for breast cancer, typically one is referring to a breast cancer that has metastasized. Metastasized forms of breast cancer are the ones primarily associated with mortality. According to the most recent Canadian Cancer Society statistics published in 2017, breast cancer is among the four most common cancer diagnoses. In Canada, mortality rates for breast cancer are at their lowest rate since 1950, while breast cancer is the second most common cancer-related deaths for females (Canadian Cancer Society, 2017). An estimated 610 women in British Columbia died from breast cancer in 2017 (British Columbia Cancer Agency, 2017).

In the early 2000s, in Canadian cancer support circles on the West Coast, it started to become apparent to me that MBC had presentations where death was not imminent. Receiving a 'death sentence' was still prevalent, but more effective cancer control options were being introduced. Some MBC subtypes have the potential to be responsive to modern biomedical technologies that extend life as well as the quality of life (Warren, 2010; Kennecke et al., 2010). In recent years, women living with MBC have been described as an *emerging patient population* (Reed & Corner, 2013; Haylock, 2010), and MBC itself as a *disease of changing status* (Lewis et al., 2016).

Next, I will discuss the emerging debate about how to categorize and to support women with MBC. I present findings of these debates through subsections on healthcare practice and empirical research. I acknowledge that these two spheres are not discrete and that there is a flow of information between the two.

Clinical Descriptions of MBC within Practice Settings

In healthcare and allied spheres of support, MBC can be considered as: a *typical cancer* in that there is a need for *control strategies* (therapeutics that control the spread of disease); a breast cancer that has spread; a palliative condition requiring comfort measures; and an ongoing illness requiring an articulated combination of surveillance and treatment adjustments over an extended timespan (K. Weber, personal communication, February 9, 2017). Metastatic breast cancer may not be a term women themselves know at first or at all. MBC is more commonly referred to as advanced-stage breast cancer, secondary breast cancer, end-stage breast cancer, spots (usually used within the BC Cancer Agency for bone metastases found by screening methods) or dying from breast cancer. Within general parlance, MBC has typically been referred to by the more generic term of advanced breast cancer, meaning a breast cancer that has spread and is either no longer curable or is suspected to be incurable.

Empirical Literature on MBC

The literature I reviewed about MBC does not ground this project theoretically; instead, this literature informs the research empirically. I sought literature that would provide an historical snapshot of MBC as a life-limiting illness, possibly one in transition. I focused on how MBC is discussed within qualitative health research since about the year 2000 because there is a discernable point of literature expansion. My search began with the literature on women's accounts of daily life, including daily life in smaller communities. There is limited research available on women's accounts. Although there is slightly more than when I first started this project in 2009, there is still a significant lack of accounts on life in community. Because my research question reflects an interest in how women with ongoing forms of MBC are produced as subjects who are living and dying simultaneously, I included in my search medical-sphere discussions of how MBC is being categorized.

In this subsection, I first discuss significant impressions from the empirical literature on MBC. Second, I present how women are currently categorized as breast cancer patients within biomedicine. I found four key descriptors; all were associated with expectations of disease trajectory: exceptional cases, survivorship (medical), curable/incurable disease, and chronic illness. Even though each of these is entangled with each other and is often discussed in association with other descriptors, each has its effects for the living⇔dying women. Finally, I discuss literature on women's accounts of living with MBC. Most of this research focuses on women who are active healthcare consumers receiving services from clinical sites. As small communities tend to lack such sites, there are few studies that focus on them. Few of all available inquiries focus on living with MBC, specifically as an ongoing illness.

Key impressions from the empirical literature. Strikingly, my review reveals the considerable *heterogeneity* of contemporary MBC. Heterogeneity is a significant factor in how MBC has been and continues to be, categorized within biomedicine. Within medical oncology, Hayes and Paoletti (2013) maintain that there needs to be a widespread understanding of how MBC does not have a singular presentation across clients. Understanding MBC in terms of heterogeneity is important because the recognition of widely varying disease processes heavily influences the framing of prognosis and disease trajectory (Bertos & Park, 2011).

Some recent discussions of heterogeneity stay within the sphere of biology. They reveal how breast cancer is now characterized by "deregulation of multiple cellular pathways, different morphology and sensitivity to various treatments" (Senkus, Cardoso, & Pagani, 2014, p. 220). An excellent example of biological heterogeneity is the Canadian research by Bertos and Park (2011). They provide a systematic review of multiple sources of tumours as part of breast cancer.

More broadly conceived discussions of heterogeneity, not confined to biological science, are valuable for contextualizing MBC. Variation in the extent of disease at diagnosis influences the course of treatment (Lim & Hortobagyi, 2016). There are currently no universal treatment protocols. Instead, there are different therapeutic approaches across organizations. Within this arrangement, there are structural barriers to service provision. Barriers include rapidly increasing cancer care costs for the subtypes of MBC (Senkus et al., 2014). There are also different ways for deciding client health status at time of diagnosis (Lim & Hortobagyi, 2016). Improved methods for defining tumours or molecular heterogeneity have revealed an even greater array than previously known (Hayes, 2016; Lim & Hortobagyi, 2016) — all contributing to the general idea of heterogeneity within MBC.

It is through these discussions of heterogeneity that the expectations of disease trajectory can be troubled. Thus, with recent molecular discoveries, it is plausible to speak of different diseases that make up what is known as breast cancer (Sledge, 2016). An argument thread taking hold in breast cancer research is to no longer view the disease as a *monolithic entity*, but as a disease that "compromises heterogeneous tumours with different clinical characteristics, diseases courses, and responses to specific treatments" (Bertos & Park, 2011, p. 3789). Senkus et al. (2014) refer to the breast cancer of recent years as a heterogeneous disease, which is the foundation for posing the question of whether it is "time for more optimism in metastatic breast cancer?" (p. 220).

The discussion thread of heterogeneity is one of a multitude of medical conceptualizations of breast cancer operating in healthcare today. In the newer literature of women's accounts, I noted two discernable ways to talk differently about MBC. First, the recently established interest in *quality of life* (QoL) for those with MBC has quickly been followed by, and often aligned specifically with, understanding women's *strategies for living well*. As more women are living longer, there is growing interest in understanding what living with MBC might be like, rather than focusing on dying from MBC. Second, more studies are focusing solely on MBC rather than citing it as an example of an advanced cancer and/or a palliative condition needing illness management.

Categorizations from within healthcare. Next, I will discuss four descriptors used to categorize MBC: exceptional case, survivorship, cure, and chronic illness. Discussions of these descriptors singularly and together demonstrate the complexities of MBC in our present moment. There are what I call 'faultlines' that are shifting classic categorizations of advanced breast cancers and with them understandings of daily life.

Exceptional case. Like other cancers, in modern medicine, there have always been women living with MBC who are *exceptional cases,* that is, women living longer than expected. These are women who do not fall within statistical norms. Who exactly fits as an exceptional case shifts with medical advancement? Now in the literature, there are far fewer discussions of women living longer with MBC as being examples of exceptional cases. I see this reduction as an historic shift. Historically, the vast majority of women with MBC who have lived months or even years beyond their prognosis have been categorized as exceptional cases.

In addition to the relative absence of this language in recent literature, a prominent leader in the medical oncology field, Sledge (2016) still uses the word exception. However, Sledge uses it to describe women with MBC who challenge understandings of incurable illness and have *long-term-disease-free survival* for years. Following the National Cancer Institute, Sledge (2016) also uses *exceptional responders* and says these are rare cases whose categorization is based mainly on response rates to specific therapeutics. Reed and Corner (2013) make the argument that those with ongoing forms of MBC are no longer exceptional cases and agree with Haylock (2010) that those with MBC are an *emerging patient population*. Reed and Corner (2015) identified three MBC disease trajectories (see pp. 362–363): (1) “ticking over nicely” (long trajectory where cancer is limited mainly to bone metastases and illness symptoms are minimal), (2) “is there no end to it” (shorter trajectory with disruptive symptoms of gradual, aggressive disease progression), and (3) “it’s a rollercoaster” (a trajectory that lasts at least 2–5 years with periods of decline as well as recovery and that is the most typical of the three). Reed and Corner’s work is a contrast to the claim by Hudis (as cited in Helwick, 2015) that across different kinds of MBC, it is only “a steady progression toward death” (p. 2) that delineates the disease. This shift in thinking both by Sledge and by Reed and Corner, identified through these trajectories, is significant in that healthcare can provide different treatment and support pathways.

When a woman who is living longer with MBC is considered an exception, it raises several questions. How might such a narrow categorization effect a woman's path with cancer going forward, including the influence on her medical care (Reed, Wheeler, & Scanton, 2012)? How does the descriptor of 'exception' work in terms of women deciding whether to seek life-enhancing options and/or to partake in current social dialogues on advanced breast cancer? Dialogues where there are a growing number of women discussing their long-term survival.

Survivorship. In general, across the popular imagination, there are normative cancer survivorship modes of both the yellow-ribbon (cancer) and pink-ribbon (breast cancer) variety. The primal arc of such mainstream survivorship is the "heroic story structure" (Ellingson, 2017, p. 321) or an arc often characterized as a masterful and hard-fought escape from death. She draws on King's (2006) critique of the corporatization of breast cancer survivorship to point out how the milieu for these "fierce medical battles" (p. 321) is "spectacular biotechnological warfare" (p. 321). Presently, ours is a social reality where general cancer survivorship has now been "breast-cancer-ized" (Bell, 2014, p. 63), and breast cancer is the definitive lens for viewing life with cancer.

In healthcare, over the past thirty years, there has been a significant improvement in cancer survival rates and with falling fatality rates, there has been "a shift in focus from cancer *victims* to *survivors*" (Ristovski-Slijepcevic & Bell, 2014, p. 166). This shift focuses on emerging health needs that are no longer defined by mortality. Survivor can be a general descriptor within medical survivorship and a classification of care (Krigel, Myers, Befort, Krebill, & Klemp, 2014).

The less cancer is associated with mortality, the more the phrase *cancer survivor* is used. Traditionally cancer survivor was for early-stage cancers where a person has successfully navigated a cancer diagnosis. Broom, Kenny, and Kirby (2018) discuss how with technological advancements, there are emerging disease trajectories that trouble tidy cancer categorizations. Thus, survivorship is about living with disease, not living beyond it. They situate these individuals as *un-survivors* who live in “categorical liminality” (p. 697) that troubles notions of both palliative and curable, and where lived experience is defined by temporal periods of waiting. A recent biomedical reframing of survivorship is, “from the time of diagnosis, through the balance of his or her life” (National Cancer Institute, as cited in Frick, Vachini, & Bach, 2017, p. 4268). In this sense, survivorship is still linked directly to death.

Within new cancer survivorship an emerging discussion is about the undesirable effects of novel therapeutics. Frick et al. (2017) detail that increasingly common are *treatment-related effects* with cancer patients living longer and that there is a need for the development of *survivorship care plans.* Treatment-related effects include fatigue, cognitive changes, and peripheral neuropathy. Ellingson (2017) argues that negative outcomes from the ill effects of present-day technologies tend to be left out of mainstream conversations. This absence profoundly influences what lived survivorship looks like publicly and suggests that cancer survivorship is not necessarily the happy ending as implied in public discourse. Thus, she advocates for a new phrase *long-term cancer survivors* (LTS), with a focus on common side effects and *material realities of late effects*.

Bell (2013) challenges modern applications of survivor to those with breast cancer because for the survivor, numbers are never merely numbers. Rather these individuals who survive have their understanding of medical information combined with their knowledge of the body. This knowledge of the body shows that for the sake of well-being, there is a need not to take biomedical technologies at face value. Bell (2013) notes that with biomedical technologies now bringing the molecular into oncology, breast cancer survivor is changing into a status defined by disease *markers* and, thus new degrees of *risk*. These are pre-disease manifestations that can affect diagnosis, prognosis, and therapeutics. Her commentary echoes Klawiter's (2008) foundational work on the biopolitics and the medical management of breast cancer, including discourses of risk.

MBC is becoming part of the discussion about survivorship and survival rates. From a medical oncology perspective, Sonnenblick, Ponde, and Piccart (2016) note, "the last 20 years of MBC treatment have been characterized by an ever-increasing arsenal of drugs and biomedical tests that have led to the prolongation of survival" (p. 1154–55). There is a trend over the 2000s of Canadian women living marginally longer with advanced breast cancer (Canadian Cancer Society, 2012). Partly because of disease heterogeneity, there is no hard and fast average life expectancy for MBC in the literature. A typical reported average is 24–36 months (Reed, Simmonds, Haviland, & Corner, 2012). Specific to my project, the statistic I quoted from the British Columbia Cancer Agency (2017) in the first chapter suggests that the median survival for MBC is 24 months. However, I have to emphasize that this rate varies widely and is becoming more varied with advancements.

Specific to MBC, Reed and Corner (2013) explored increasing complexities associated with the disease and then recommended that some subsets of women now need to be considered survivors. For many of those living longer with MBC today, their lives can be described as an “odyssey of personalization” (Sonnenblick et al., 2016, p. 1147). In other words, breast cancer survivorship is demarcated by individual therapeutics. Originally from the larger body of literature on advanced cancer (Berlinger & Flamm, 2009), *progression-free survival* is now being used for delineating subtypes of MBC responsive to today’s therapeutics (Parisi, Pelletier, Cherepanov, & Broder, 2018). Throwing into doubt reports of longer survival with MBC are limitations with available statistics and also counter-reports. As mentioned in Chapter 1, within an uneven statistical landscape of MBC survival rates, there is a growing healthcare debate over survival within MBC, including whether women are living longer.

Other questions arise about the applicability of survival rates for MBC, given how today’s volume and speed of therapeutic advancements are shaping living⇔dying reasonably quickly. Survival rate improvements with MBC are moderate compared with early-stage breast cancers (Lim & Hortobagyi, 2016). Doubtful of reports of longer survival, Sledge (2016) presents a counter statistical report that shows survival rates for MBC not changing over the past few decades. Within Canada, five-year survival rates for MBC are at 22% (Canadian Cancer Statistics Advisory Committee, 2018). This is only incrementally different than the other national cancer statistics from this past decade and is still much lower than for stage 1 breast cancer, which is close to 100% (Canadian Cancer Statistics Advisory Committee, 2018). Addressing the need for clarification, a growing trend is to gauge MBC survival by specific tumour characteristics (Hao et al., 2015).

With cancer survivorship in broader society, a practical consideration is what life is like for women who are living⇔dying with MBC today. Ristovski-Slijepcevic and Bell

(2014) caution that the application of survivor status “makes invisible the experiences of people with metastatic disease, many of whom are living longer. They have not ‘beaten cancer’ or ‘survived it’ in the sense of being declared disease-free but nor are they terminal” (p. 167). Given how survivorship is no longer simply something women with MBC are socially excluded from, but something that they may find themselves in negotiation with over time, what are some of the day-to-day effects for them? How does the label of survivor fit with regards to women’s hopes, health maintenance, and other day-to-day actions linked with either a cure or the lack of a cure?

Cure. In the literature on curing MBC, I found there are at least two significant shifts: a renewed debate on cure and curability and some qualifications on what an incurable disease is.

First, within MBC discussions, there is polarized dialogue on curability. MBC is never free of the intense medical gaze that focuses on *curing* cancer. What curing may or may not mean for women becomes more complicated as ongoing forms of MBC continue to defy what counts as a cure, while being responsive to modern medicine. Such illness malleability offers glimpses into MBC as possibly being considered as a nonfatal disease.

Some recent MBC debates now feature a complex notion of cure. Within medical oncology, Sledge (2016) and Hayes (2016) both pose the question of ‘what is cure?’ given the various forces at play in today’s medicine. Sledge continues, “does cure include conversion of metastatic breast cancer to a chronic disease?” (p. 6). Such a shift redefines MBC in terms of its curability. Likewise, Davidson (2016) uses the language of “long-term cures,” which is a direct reference to the increasing array of options that can forestall disease advancement. Insisting there is still a long journey to curing MBC, Sledge (2016) points out several potential paths that already exist in MBC care. including successes of modern adjuvant therapies.

Second, within MBC discussions, there are also qualifications on what constitutes incurable. MBC has been described as an example of an illness that is "incurable, but treatable" (Frick et al., 2017, p. 4275). This type of language references the new biologics potentially offering extended life without ridding the body of cancer (e.g., Frick et al., 2017; Thorne et al., 2013; Maher, Velikova, & Betteley, 2015). In this way, some cases of MBC fall within a cluster of cancers, which commonly includes prostate, ovarian, myeloma, and some cases of lymphoma (Maher et al., 2015).

How is it for women living long-term with MBC to live with questions about its curability, in addition to the conventional uncertainties of metastasized breast cancer? What is it to live each day with the awareness that one has the potential for well-being, but not of being cured (Willis, 2013)? How do women embody and remedy such contradictions in their day-to-day lives?

Chronic illness. With biomedical advancements throughout the 1990s, cancer as a disease changed its presentation and started to be more regularly considered as a chronic illness (Thorne et al., 2002). Today MBC is one of the cancers that is being included increasingly in conversations on chronic illness. There is also how MBC is part of a larger trend in North America of more people "living long in fragile health" (Lynn, 2005, p. S14). Given how prevalent life-limiting illness as chronic illness is becoming, there is increasing attention by healthcare, as evident in research and at both government and front-line practice levels (Carstairs, 2010). However, healthcare services have struggled to keep up with the pace of new therapeutic modalities and extended-life outcomes for MBC patients

(Reed et al., 2012b). There are evolving questions as to how to meet the needs of such individuals best. The changing status of MBC implies that there is a need for clinical disease management to address long-term stabilization measures (Reed et al., 2012a; Orlando et al., 2007; Arnada et al., 2005).

With MBC and the other advanced cancers being framed as chronic, there is debate whether prolonged survival with cancer can genuinely be described as a chronic illness. Speaking at the time when chronic illness was first being applied to cancer, Tritter and Calnan (2002) documented how cancer experiences are distinct from what has been known as chronic illness even though there are shared characteristics. Cancers are distinguished from typical chronic illnesses in that individuals living longer with cancer were 'living in contracted time' (Mosher et al., 2013; Bell & Ristovski-Slijepcevic, 2011) and went in and out of cycles of acute illness and how life was a "mystifying embodiment of living and dying" (Jain 2007, p. 78). Tritter and Calnan (2002) argue that if cancer could be categorized as a chronic illness, it would not be one in a traditional sense. Their reasons include periods of chronicity that are interspersed with acute illness; the complexity of disease treatment crosses multiple disciplines, and cancer is still entwined with death in the public imagination. Further, they emphasize that if considering the categorization of chronic illness with patients, there needs to be an understanding of the experiences of the individuals themselves. Likewise, in her discussion of why social labels matter with cancer, Bell (2013) notes the ambiguous fit of cancer with chronic illness. She describes how cancer rivals HIV/AIDS as an ongoing illness that evokes potent fears about dying and, at diagnosis, cancer is characterized by acute and rapid responses from healthcare services. Like Frick et al. (2017), Watson (2014) applies the term *chronic cancer*, however she delineates a “liminal world” where individuals, “inhabit the space between these two extremes (curative cancer or dying of cancer)” (p. ii).

Some types of advanced cancer are now medically managed as a chronic illness, which in practice is a client group that is rapidly growing (Harley, Pini, Kenyon, Daffu-O’Reilly, & Velikova, 2016). Survivorship is linked to managing cancer as a chronic illness. Frick et al. (2017) uses the designation of chronic cancer or CC as one example of potential survivorship outcomes and draws attention to look after survivorship needs. Likewise, Mogghadam, Coxon, Nabarro, Hardy, and Cox (2015) found that unmet needs of advanced cancer patients now resemble the needs of individuals with chronic illness, including: “(1) information deficits, (2) preoccupation with worries/uncertainties, (3) fatigue and pain management and (4) loss of functioning” (p. 3620). These unmet needs play out differently across healthcare environments. Specific to West Coast British Columbia, Syme (2011) detailed a support gap between cancer control and palliative care systems. This gap sets up a growing number of patients who have chronic forms of advanced cancer to fall between systems and get lost in the means through which healthcare is delivered.

Attempts to refine control strategies for non-curative disease management are leading to new ways of holding cancer as a progressive disease process in suspension (Lage & Crombet, 2011). Harley et al. (2016) reported that cancer was poorly defined as a long-term illness experience and support needs were not well known. Because in part, aspects that made long-term survival with cancer its own kind of chronic condition, were not well explored and/or acknowledged. Within the medical literature and the healthcare practice community, advanced cancer is an illness that has had a well-established illness trajectory. However, new manifestations of the disease are disrupting conventional expectations of acute onset and established prognostication strategies (Reed & Corner, 2013; Thorne, Oliffe, Oglove, & Gelmon, 2013). There are an increasing number of individuals with advanced cancer, across a growing number of various types, who now have a lengthy period of relatively stable health followed by decline (Lage & Crombet, 2011; Haylock, 2010; Lynne & Adamson, 2003).

Specific to MBC and how it is medically managed, there are concerns about applying the label of chronic illness to more cases. Given that the usual path of ongoing MBC is defined by a reliance on sequential drugs prescribed over several years, Sledge (2016) argues this disqualifies MBC from being considered a chronic illness, as most in medicine would define it. In a similar vein, Hudis (as cited in Helwick, 2015) describes modern therapeutics as "more likely 'delaying the inevitable'" (para. 21) when it comes to death and living with this "'constant ongoing risk'" (para. 2) defines life with MBC. Ironically, one of the disease's few certainties is that it is often difficult to discern, at the time of diagnosis, who will live longer and who will not, complicated by the randomness of disease processes and responses to treatment (Warren, 2010). Overall, framing some MBC subtypes as chronic illness might impose a set of relatively fixed understandings of an illness that is already not well understood.

Given the current chronic illness debates, what challenges exist for women with suspended MBC as they try to speak of what they bodily know? Providing a sense of the complexities at play, there are new phrases to describe people with cancer who have an ambiguous relationship with their mortality and wellness, such as *the chronically dying* (Lage & Crombet, 2011) and *the conflicted dying* (Mohammed, Peter, Gastaldo, & Howell, 2015). Phrases like *advancing chronic life-limiting conditions* (Stajduhar & Tayler, 2014) allude to bodily paradoxes that those with these illnesses may experience. Living in suspension, including the phrases on offer to them, what tensions of social fit do women encounter in the-day-today, in their smaller communities?

Accounts of living with MBC from women themselves. There is a vast and rich body of literature on breast cancer. Most of the research focuses on early-stage breast cancers. Few studies specifically focused on metastatic breast cancer (also referred to as secondary breast cancer or advanced breast cancer). Of the existing literature, most of the studies are quantitative and focus on aspects of MBC specific to disease processes or clinical treatments for medically designated concerns, such as depression. Many of these focus on the time around diagnosis. There is a limited range of studies specific to women's psychosocial needs or other elements of what it is for women to live with MBC day in and day out. There are few that focus on accounts of the women themselves, accounts speaking to the range of experiences or realities of life with MBC. Fewer still provide a critique of social dimensions that impact women's lives, shaping their experiences. There is an overall lack of research that focuses on or includes small communities, including daily life.

In approaching the body of literature, I kept a critical lens specific to how women with breast cancers tend to be presented in the research. Like with early-stage breast cancers, the literature on women's stories of MBC tends to be positioned as either women's *experiences of* or *lived experiences of*. An outcome of such positioning can be that women with MBC are cast outside their embodied realities with a life-limiting illness. Poststructural critiques of using individual experience have shown that such readings can be ahistorical and disembodied. Without the nuances of a particular time and place, the experiences may lack substance and can only be acknowledged as an interpretation of *individual* accounts (Scott, 1992). The use of the term ‘experiences’ can be deceptive in how they may be positioned as providing definitive insight and truth about what women (can) live with. The term can also operate as a pressure for women’s stories to have the shape of normative discourses about cancer. Overall, ‘experiences of MBC’ can be problematic in creating containable stories that refine or exclude embodied nuances of day-to-day life. Such accounts can be oversimplified stories of daily life with MBC. Keeping the above caveats in mind, I focused my attention for this project on: what do women’s accounts have to say about day-to-day life, and how are women with MBC positioned?

Scope of the research. Two literature review articles provide a sense of the scope of the research that has been undertaken about women’s accounts of living with MBC and how women with MBC are positioned. The first is a secondary analysis of literature on MBC and emotional functioning. Searching between 1984 and 2010, Warren (2010) identified 26 studies that touched on women’s accounts. Of these, 9 were qualitative studies, and 3 were mixed-method studies. Within the reviewed studies, there were three recurrent themes: multiple facets of uncertainty, lack of control generated by multiple social and interpersonal factors, and poor emotional functioning when compared to primary breast cancer. Warren (2010) concludes that the lived context of MBC for women is one of ambiguity, stigma, and uncertainty. Mortality may or may not be in the foreground for women; however, MBC is cast as an undesirable experience of unmet needs. Warren also notes that more qualitative research is needed to help identify issues women are living with to develop interventions. Second, Willis, Lewis, Ng, and Wilson (2015) conducted a systematic review of both quantitative and qualitative literature from 1984–2013 on women’s accounts. These researchers specifically wanted to know the “extent to which the experiences of women with MBC have been investigated" (p. 516) and to examine what was the focus of each of these studies. They found that since 2000 there was a new general research focus: away from specific dynamics of dying and towards a focus on "negative experiences and adverse health and quality of life outcomes of women with MBC" (p. 537). From their review of qualitative literature they identified a similar, yet more precise, set of themes: "living as a social outsider; importance of hope; health, and quality of life; positive experiences; experiences at end of life; and strategies for living" (p. 514). In this review, the overall depiction of living with MBC as characterized by undesirable aspects is tempered with what women might do in response. Both systematic literature reviews show the extent to which there has been both a lack of qualitative research and research on women's accounts with MBC. They also show how few research studies, included or focused on the subgroup of women who have lived with a metastasized breast cancer long-term, either those living well or those who are not. Also, they show how there has been a lack of research in smaller communities. Among the studies that included a prolonged form of MBC, none focused on smaller communities, whether described as rural, non-urban, or small.

There is growing interest in research exploring women's accounts of living with MBC. With biomedical advancements and improved medical management, leading to women living longer with MBC, there is increasing research interest in women living with MBC. Few studies have yet to be specific to everyday life. Setting in motion findings of different MBC illness trajectories (Reed & Corner, 2013, 2015), Reed (2012) in her doctoral research, explored how women with MBC live their day-to-day lives, including social consequences of MBC. She found that women "mediated discontinuity between the self, body, and social order and how they navigated the oscillations of a life lived with progressive breast cancer" (p.101). Maintaining social roles was a pivotal part of that story. Krigel et al. (2014) found that having MBC equalled dramatic changes across women's lives, including concerns around their roles, relationships, and self-image. Specific to their illness, these women faced uncertainties around medical management of illness and lack of information. Making a break from earlier research on MBC that focused on early diagnosis and associated negative responses, Lewis et al. (2016) discussed women with MBC as living with a lifetime of treatments and questions around what their life might be like. They found women had three different approaches to how to live as well as they could with MBC: returning to some kind of normality, revaluating their lives and changing directions, and staying much the same because of symptoms that restricted their options.

Across the available literature, I found that life with ongoing MBC is cast as a mosaic of uncertainties, around one's health and possible futures (see Lewis et al., 2016; Thorne et al., 2013; Bell & Ristovski-Slijepcevic, 2011; Vilhauer, 2008). This overarching theme of uncertainty is in line with Shilling, Starkings, Jenkins, and Fallowfield's (2017) inquiry on aspects of life and wellbeing with advanced cancer patients, which found that uncertainty was pervasive among women's accounts. This uncertainty takes on many forms and primarily arises from having a lack of a clearly delineated disease trajectory. Uncertainty linked with time is also echoed in Krigel et al. (2014) whom found that although women with MBC are living longer, they typically live with a compelling sense of the unknown, generated by not having a clear sense of how long they will continue to live.

Living with treatment side-effects and having a need for information about MBC are salient threads of living with uncertainty. Daily life with MBC is often punctuated by the side-effects of treatment modalities that act like disease symptoms. Women tend to self-navigate these effects with little support from healthcare practitioners (Lewis et al., 2015; Vilhauer, 2008). There is a documented need for paying more attention to the side-effects of novel therapeutics that women with MBC encounter (Lewis et al., 2015), including how women living with MBC face daily questions about the bodily impact of therapeutics and whether or not it is worth it (Broom et al., 2018). As with other ongoing or chronic health conditions, daily life with suspended MBC includes continually learning about the disease and managing information. This learning may include the technological advancements in detection, diagnosis, and treatment, and the services available for managing the disease. Living with metastatic breast cancer comes with issues around the lack of information that contribute to uncertainty, including on possible treatment options and symptom management (Krigel et al., 2014). While women with MBC reported that they rely heavily on oncologists for information, they also rely on non-medical sources (Willis et al., 2015). With MBC, Shin et al. (2016) reported that poorer quality of life was commonly associated with a lack of accurate prognostic understanding and related information.

A growing trend in the literature within women's accounts of MBC is a focus on well-being and quality of life (QoL). It is common that this literature directly addresses the healthcare management of MBC, including better understanding the needs of women to improve interventions. Luoma and Hakamies-Blomqvist (2004), in their interview study on quality of life, found that women being treated for advanced breast cancer mediated issues of autonomy. These included tensions between physical limitations and dependency on others. Also, of key importance were women's need for both personal growth and hope. Women often expressed their global QoL by talking of a normal life. Aranda et al. (2005)

focused on women who had an affiliation with a large urban hospital and on how QoL findings could guide improvements in healthcare provision (e.g., counselling services). They found that the highest unmet needs of women were in the psychological and information domains. Mortensen, Madsen, Krogsgaard, and Ejlertsen (2018) note that modern MBC consists of a wide range of both psychosocial and physical needs not well met by healthcare services. They observe how for women, MBC is now a disease of "perpetual adaptation of their QoL standards" (p. 146). Krigel et al. (2014) reveal QoL difficulties that come from living in uncertainty, including disruption of roles, changes with relationships and self-image. They argue that a multidisciplinary approach is needed to address the diversity of needs reported as part of quality of life. With QoL, Mosher et al. (2013) distinguish between women with ongoing MBC who are experiencing significant distress and those who are not. This distinction is an important counter-story to prevalent oncology narratives where women with MBC are often portrayed as dealing with significant and ongoing emotional burden.

Connected with well-being and quality of life inquiries is a new body of research that identifies strategies for living well with MBC. In this literature, there is often consideration of established chronic illness and coping, whether referring to or focusing on strategies for living well. Lewis et al. (2015) stressed that women living with ongoing MBC have care needs that exceed the medical management of symptoms. As a result of these needs, the women engage in various strategies to discover how to live life as well as they possibly can. The most common strategy is the restoration of a sense of normality, accompanied by a process of re-evaluation and re-prioritization in their lives. Strategies used by women with metastatic cancer who were raising dependent children differed from those used by older women. Younger women attempted to create normalcy within their household and they faced temporal choices around parenting goals and how to leave memories (Bell & Ristovski-Slijepcevic, 2011).

In my project, I acknowledge how strategies for living well, as part of enhancing or maintaining QoL, can be problematic when applied uncritically, or when it serves only as "a limited framework through which life can be described and experienced" (Ristovski-Slijepcevic & Bell, 2012, p. 167). Quality of life can also position those with cancer as passive patients, leaving out their agency as individuals (Mohammed et al., 2015).

Studies on women's accounts that offer critique. There are few studies to offer a critique on social dimensions and living with MBC specifically, rather than breast cancer in general. The formative research in this regard is that of Gray and colleagues in the early 2000s. They documented that there were many challenges for women with advanced breast cancer in a society where early-stage breast cancer now had a celebrated social profile that did not fit life with advanced stages (Gray, Sinding, & Fitch, 2001). Women in that study expressed a need for the seriousness of MBC to be acknowledged by others, for moving beyond a biomedical approach in considering their needs (such as statistics), and for not confining them to tropes of survivorship, such as heroic or meaningful journey. Conducted at the height of the breast cancer movement in Canada, their research documents tensions between the realities of women's daily life with MBC and what was then the new "upbeat image" of breast cancer, including mainstream discourses of *spunky survivorship* (Gray, Sinding, & Fitch, 2001; Sinding & Gray, 2005). They revealed how mainstream narratives operated to both illuminate and obscure social realities of MBC and outcomes in women's experiences of illness, particularly how framings of "normal" for women with breast cancer often did not resonate with the actual lives of women with MBC. Their work resonates with how Villhauer (2011) found that women with MBC did not find mixed-stage breast cancer support groups helpful, primarily because of an “us/them” dichotomy between women with early and late-stage breast cancer. Overall, Gray and colleagues’ revealed ethical and political concerns of contemporary life with MBC, opening new curiosities.

There are also more recent critiques specific to women’s accounts that provide nuanced insights into women’s lives with MBC. Bell and Ristovski-Slijepcevic’s (2011) ethnographic research on mothering while having a metastasized cancer included women with breast cancer. They discuss how mothers living in a “contracted future” (p. 629) face an unresolvable bind between the social expectations of mothering and the day-to-day realities of having an advanced cancer, including negotiating the need to maintain facades of normal as both a parent and a woman with cancer. Davis (2015) used a case study to show how stories of women with advanced breast cancer tend to be missing from breast cancer survivorship culture, and silence is often their story. Their stories tend to be silenced by the workings of dominant discourses on survivorship. Jacobson (2018) provides an analysis of “metavivors,” a new category of survivor that covers women with advanced breast cancer who have been left out of mainstream breast cancer narratives. She used an ethnographic approach to show how these women use social media to share their stories and, in so doing, expand on available illness narratives. Based on these women’s accounts she describes them as occupying, “a liminal position between a fatal disease and one that may become a chronic condition in their lifetimes, thanks to rapid advances in medicine” (p. 18).

Summary. In this section, I discussed how the breadth of the empirical literature on MBC over the past twenty years comprises a set of questions that need further exploration. In general, the literature speaks to a transitional milieu for MBC. It is shifting from being primarily life-threatening with imminent death, toward being a life-limiting illness with expanded possibilities for living longer. A bird's-eye view of the medical literature on MBC suggests that given molecular advancements, including in diagnosis, as well as the cascading effects of treatment modalities in medicine, MBC as a disease occupies precarious categorizations as debates emerge over client needs. Amidst all this change, there are still few accounts of what it is like to *live with* MBC by the women themselves. Where individual accounts do exist, there is limited insight into whom they have become and what they need to live well with MBC. For women living longer in small communities, there is a distinct lack of insights. I share with the existing literature a keen interest in the health needs of women with MBC. One of the ways my project contributes is that I come from a different place in the therapeutic constellation of healthcare, one that holds both a practitioner perspective and a focus on smaller communities. I also offer a different take on living with MBC by having a theoretical approach imbued with critical consideration of factors that inform daily life for women with MBC.

Thinking Differently about MBC: Language use in this Project

In the last section, I reviewed the ways that biomedicine describes MBC and what this approach to describing MBC leaves out. My research question guides me to look at how women with MBC are produced as subjects who are simultaneously living and dying (living⇔dying) through these medical descriptions of the disease. Also, my research queries how this process of subject production might restrict or expand women's potential for living well. Language, as part of discourse, plays a role in producing the subject. Indeed, there is a general lack of a framework for language that is up to the task of contemporary complexities with MBC (Bell, 2013). Thinking about the existing literature and the status of MBC as a life-limiting illness today, in my research project, I go beyond MBC as delineated as a pathological entity by positioning women as part of a nexus of social forces and materialities. Mine is an inquiry attuned to the critique-informed notion of women with MBC as living "in the face of a contracted future" (Bell & Ristovski-Slijepcevic, 2011, p. 629). These women lead lives increasingly mediated by biomedical technologies, where life may be sustained, but in doing so, the shape of living may be different than what had been expected. One of the tenets I work from is the understanding that how MBC is spoken about as an illness will likely influence the ways women think about and manage their daily lives (see Thorne et al., 2013).

In this section, I present the language I have chosen to use to speak about MBC. I try to hold onto the notions of MBC as being embodied and generated through both language and the materiality of the body. I use metastatic breast cancer, life-limiting illness, and suspended. Elaborating my use of language in this way helps me situate the project within wider debates about MBC. My use of these terms does not offer a new lexicon nor is it intended to be definitive in any way. Instead, I use these terms as points of entry into the complex ways I am trying to talk about living⇔dying for women with MBC.

Metastatic Breast Cancer

Rather than the more general phrase of advanced breast cancer, for this project, I am using metastatic breast cancer. Informing my choice is my background in psychosocial oncology. Within clinical healthcare resources and empirical research studies, there is no one exact definition for advanced breast cancer. In application, advanced breast cancer is commonly a basket term that functions as a voice from nowhere, in that it does not speak to specifics of social and bodily experiences. Some forms of advanced breast cancer do not fit with my project interest of living⇔dying. Contemporary MBC does. However, I acknowledge that with MBC, there is greater precision without being perfectly exact, because there are several subtypes of MBC. These subtypes are in addition to the underlying unknowability with breast cancer disease in general.

In this project, my use of the term 'metastatic' functions in four ways. First, I use metastatic as a definitional and categorical boundary to capture the medical realm of both cancer and breast cancer. In healthcare settings, MBC is not the only type of breast cancer to be considered advanced or to have that descriptor applied to it. Stage 3 breast cancer is sometimes referred to in this way because it too, involves disease progression. However, my use of the term MBC is meant to hone in on that part of the disease process where women are most attuned to living⇔dying processes. The descriptor metastatic brings with it a particular gravity. It is a biomedical term that references a specific cellular process and its various effects.

Second, the use of MBC acts to emphasize the disease's dynamism after it has metastasized and gone beyond stage 4 breast cancer. The etiological root of metastatic means movement in the sense of transition. Bearing in mind both the wide range of movement and the potential for movement itself highlights bodily uncertainty associated with MBC. Under the medical gaze, whether by human eyes or technology, even if MBC does not appear to be actively advancing, it does not mean cancer does not move or transition to something else. Emphasizing movement, as part of the bodily framing of MBC, supports thinking beyond the traditional static parameters of cancer toward the embodied messy landscapes of women living in the day-to-day.

Third, my use of metastatic is a way to put language to work so it ignites and expands thinking more precisely about MBC. Part of my relational materialist research purpose is to see what subjects (in the Foucauldian sense) are generated through the women's bodies and the talk about the women's bodies with MBC. For me, thinking differently about MBC assists in addressing the connections and intersections between living⇔dying and what subjects emerge from this site.

Fourth, my use of the term metastatic is a kind of breast cancer advocacy defiance. In an era of widespread breast cancer awareness dominated by survivorship, metastatic is a concept still saturated with socially undesirable properties. It can be associated with falling out of cancer survivorship status. It can be associated with suffering, or at least the 'overcoming' of suffering. It can be associated with death. Equally problematic, yet encouraging, the term metastatic is also now part of an emerging social trend of MBC awareness outside the conventional confines of survivorship. For example, commercials for effective MBC treatment on mainstream television include detailed accounts of what constitutes the spread of cancer that can be treated (see also https://www.metavivor.org for a breast-cancer style juggernaut in American MBC awareness campaigns).

Life-limiting Illness

I am interested in the ways women take up the various dimensions of living⇔dying. Within these debates, I situate MBC as a life-limiting illness, rather than a life-threatening illness, serious illness, or any other alternative from the literature. My choice here is a pragmatic one, it is informed by both my social work background and Braidotti's theorizing. I wish to draw attention to the ways MBC may be limiting hopes of a life that could be otherwise for women living⇔dying with MBC. In her work, Braidotti (e.g., 2013, 2012) discusses what life may be, in its materialities and potentialities, and how it may be other than what it is. The same goes for dying — living gives insight to how one may self-style their own dying (Braidotti, 2012). This framing of life-limiting illness focuses on life in the present moment and all the life that can be lived, even while dying. In this project, I found it useful to think of MBC as life-limiting so that I could speak about the permutations of living⇔dying with women in smaller communities.

Suspended

Like the women who were living long-term with MBC who I was familiar with, I went into my project not entirely certain of how to describe ambiguous forms of MBC. However, I was sure that whatever descriptor I chose would be provisional and subject to change as the research continued to develop. I also knew I needed a descriptor beyond a biomedical perspective. I wanted to use one that the women might relate to, based on their own knowing. Dr. Jesse Pewarchuk (who in our conversation agreed to be identified in this dissertation, personal communication, March 7, 2018), an internal medicine specialist who often works with breast cancer in bone and who is a key informant for this project, said to me "cancer never stops." He said that cancer is always looking for a way around the therapeutics (and/or other constraints) — and it will eventually find one. His depiction of cancer resonated with how the women I knew of lived with a lingering presence of cancer, whether they had distinctive symptoms or not. Thus, I am framing ongoing MBC as being held in abeyance or suspended in some way. I am not framing MBC as dormant, as is common in discourses about cancer care and survivorship. Such suspension is imbued with a sense of waiting, not only at a cellular level, but also socially. In this way, suspension retains a sensibility of movement even while seemingly standing still. The notion of movement is a welcome resonance between my use of suspension and my use of metastatic in this project.

How I am Positioning MBC in this Project

In working to find ways to speak of MBC for this project, I situate MBC as a life-limiting illness embedded in an evolving landscape of detection, diagnostic, and treatment modalities. My project is an inquiry of living⇔dying. Knowing the scope of outcomes for women is a challenge, especially considering emerging trajectories for the disease and disparate prognostications for life to come. There are also different ways MBC is socially and culturally positioned as breast cancer survivorship changes within the Global North, where my study is located. In this transitional landscape, there are clues as to new ways to think about MBC that can better support women. My curiosity fuels my overall project in figuring out how to speak of the types of MBC that over time do not advance, instead become something other than what they have previously been understood to have been.

It is in the work of positioning MBC and finding ways to talk about it specific to contemporary contexts, that I first discovered Braidotti's relational materialist approach and then eventually chose to apply it. Considering the general trend of people with life-limiting illness living longer, Nissim et al. (2012) suggests there is the need for cancer research “to produce ‘the language, the categories, and the stories’ (Lynn, 2005, p. 14) of those with a prolonged trajectory of dying” (p. 385).

Conclusion

In this chapter, I have discussed ways MBC is spoken about in the medical literature and in the overall landscape of life-limiting illness upon which women with MBC are living⇔dying. I have also discussed how I am speaking about MBC and positioning it in this project. Such discussion is important as the language of MBC itself sets up those who are living⇔dying to think about MBC in particular ways. Part of considering and reconsidering how MBC is discussed, is accounting for the ways that time matters with MBC today, as does access to resources. In the next chapter on theory, I go further into finding ways to speak about MBC by discussing a feminist materialist theoretical framework and how it supports my project’s specific research question.

Chapter 3: A Feminist Materialist Theoretical Framework

> It matters which stories tell stories, which concepts think concepts ... all the thousand names are too big and too small; all the stories are too big and too small. As Jim Clifford taught me, we need stories (and theories) that are just big enough to gather up the complexities and keep the edges open and greedy for surprising new and old connections.
>
> — Donna Haraway (2016a, p. 101)

My research project focuses on the underexplored area of women living with ongoing metastatic breast cancer (MBC). In a shift away from more conventional social science approaches, I frame my focus on MBC as living⇔dying, where I understand the women as living within boundaries of life and death that are changing. To this end, I have crafted a theoretical framework open to “surprising new and old connections,” as suggested by Haraway (2016a, p. 101). My framework is primarily informed by Rosi Braidotti’s relational materialism, a kind of critical thinking that accounts for complexities of serious illness today (Bell, 2013). Including critique of how contemporary technologies are changing diseases (Braidotti, 2013). My adaptation of Braidotti’s compassionate and critical investigation can open new ways to speak of MBC providing fresh insights into daily life with living⇔dying.

In this chapter, I lay out the specifics of the theoretical framework I will work with in my project. Discussion includes, how in my project, I utilize threads of the wider-ranging feminist materialities movement, of which Braidotti is part. I also discuss my framing of the relational living⇔dying subject that guides my analysis presented in Chapters 5 and 6.

Cultivating Complexity: Working Toward Stories that are 'Just Big Enough'

There are many research studies that explore the experiences of people with illness. By design, these inquiries are qualitative. They provide empirical snapshots of people's lives and tend to offer an analysis of social factors. Breast cancer has a wide constellation within this body of research. Not surprisingly, the emerging research on living with MBC often takes the form of studies on experiences of this illness (e.g., Lewis et al., 2015). These accounts of MBC create norms around both what the illness is and what we might think it is to live with it.

Building on this literature, I wanted to cultivate more complexity within accounts of MBC. I 'cultivate complexity,' in part, by turning my attention to underexplored realities of women's day-to-day lives with MBC, not least of which is the social context of life in a smaller community. I also cultivate complexity by creating analytical space for an exploration of the margins or stories that sit outside normative understandings of what experiences of advanced cancers are. Finally, I cultivate complexity by conducting life-limiting illness research while critically engaging normative biomedical parameters or expectations. Through these acts, my project is a critique imbued with the goal to accentuate women's lives and not sacrifice nuance in stories.

Over time, my inquiry took to heart that "it matters which stories tell stories" (Haraway, 2016a, p. 101). Within most Western societies, MBC has been a stigmatized illness associated with death and coded primarily by silences, that is, not often discussed directly, if discussed at all. However, in a growing number of social spaces, MBC is now also *part of* normative narratives, such as survivorship. I found a way of engaging suspended

MBC is to think about how stories matter, including what might be ‘just the right size’ of stories.

One of my story-specific goals is to speak to the evolving commonplaceness of MBC and its ramifications for women. I draw inspiration from multi-genre author Helen Humphreys, who has also worked with enlarging the narrative on a commonplace topic, in her case apples. Humphreys’ goal is to shift the focus on the topic, going outside of normative stories, and to produce what she calls a *hidden history*. For example, she wrote about apples by juxtaposing perspectives of women, indigenous peoples, and artists to reveal a history of apples, not part of mainstream conversations (Humphreys, 2017). In my project, I looked not so much to produce a hidden history; instead, I sought to expose a *hidden presence* of women within MBC. That is, by thinking about how stories mattered. I sought to disclose the varying facets of living⇔dying as these women embodied them, facets likely not generally known by others. In other words, I was curious about those aspects of uncertainty that may distinguish suspended forms of MBC from more acute presentations. How does one access these facets? The theoretical frameworks best meeting my research goals were those offering an analysis of power relations that produce particular subjects; and those using revitalized conceptualizations of embodiment, body, and the bodily. Thus, I turned to feminist poststructuralism.

With feminist poststructuralism, I found an advocacy-driven critique interwoven with how to cultivate complexity through embodied and embedded accounts. I found conversations on the challenges of sharing women’s stories. For example, debates about both voice and representation were critical in understanding women’s lives (e.g., St. Pierre, 2009). I also found discussions on how to stay open to story accounts that could not have been anticipated within research design, including both challenges to over-instrumentalization of research queries and in-depth conversations of how to use qualitative inquiry as invention and not convention (e.g., Lather & St. Pierre, 2013; Jackson & Mazzei, 2012; St. Pierre, 2011). Most of all, as a social science researcher I found a means to engage critique in my work on living⇔dying, as well as a sense of solidarity with others who had taken up "productive analyses provided by the 'posts'"(St. Pierre, 2014, p. 3).

Turning to Material Feminisms for Generative Inquiry into Women's Lives with a Suspended MBC

While reading poststructural feminist theory, I discovered the literature on emergent material feminisms and the wider ontological turn. It was clear that there was a renewed and growing interest in matter/materialities/mattering. This literature helped me understand how MBC as living⇔dying worked to produce women as particular types of subjects. Material feminisms reconsider the privileging of "language, discourse, culture, and values" (Coole & Frost, 2010, p. 3). They move toward understanding matter as different from older philosophical traditions, bringing matter to the fore of analysis alongside discourse. Conceptualizing the material with the discursive can "once again give material factors their due in shaping society and circumscribing human prospects" (Coole & Frost, 2010, p. 3). As part of these material factors, bodies become important as material and discursive entities, thus bringing into the debate "the place of embodied humans within a material world" (Coole & Frost, 2010, p. 3).

Material feminisms have rapidly expanded over the past decade and are highly influential in the critically-informed scholarship of materiality (Coole & Frost, 2010).

Importantly, such theory "allows us to forge ethical and political positions that can contend with numerous late-twentieth-century/early twenty-first-century realities in which 'human' and 'environment' can by no means be considered as separate" (Alaimo, 2008, pp. 238–9). These material feminisms are not to be confused with earlier Marxist feminists who have had a long-standing interest in matter, often informed by economics in terms of production and reproduction (e.g., Maxine Molyneux). The emerging material feminisms are interwoven within contemporary framings of the human body and natural world as well as technology. Material feminisms often critique technological advancements specific to our current era of advanced capitalism.

Material feminisms are further distinguished by ontological framings that are *interactionist*, meaning materialities are processual and relational. There is no static philosophical presumption of a stable conceptualization of space wherein discrete entities join together. Instead, material feminisms seek to undermine this static framing and unravel the *material-discursive* dimensions of individual lives and social processes (for example, see Thomas-MacLean & Midema, 2005). Within material feminisms, analytical attention is directed at interrelationships of the material and the discursive. That is, analysis is oriented towards something more akin to understanding the relationship as *material⬄discursive* (for example, see Jackson & Mazzei, 2012, Chapter 7).

Often material feminists build on Foucault, framing discourse as part of an ontology at work. What materialism feminisms bring into this discussion is a critique of the production of subjects particular to our contemporary times. As discussed by Barad (2007) an underlying tenet of the approach is that "discourse is not literally what is said. Discourse is what enables and constrains what can be said" (p. 146). As well, materiality is an active *doing*, and just like discourse, matter is not just produced (in a Marxian sense), matter produces subjects. Matter is “a dynamic and shifting entanglement of relations” (Barad, 2007, p. 224) and is agentic (read as having agency). Thus, the story told cannot be reduced to either discourse or matter, just as it cannot be restricted to subject or object. Within material feminisms, stories include all of these things in very specific ways. Thus, material feminisms support stories that can be told that are not too big or too small. Alongside these analytical possibilities of a material feminist approach is that it is a feminism looking beyond the site of gender (Lather, 2012). There is an expansive engagement with “feminist understandings of the political” (Barad, 2011a, p. 7) that assists in understanding phenomena outside of the construct of gender. Højgarrd and Søndergaard (2011) suggest there is sustained concern throughout inquiry, rooted in a materialist feminism, for “how normativities of socio-cultural categories work on, in, and through, human beings; as well as how matter or materialities and technologies enact and are enacted in these processes” (p. 340). Although my inquiry is about women living⇔dying with MBC, gender is not my central analytical focus. Like many material feminist inquiries, the focus is not on women *per se* or any other bounded identity. Instead, my analytical focus is on the stories that can be told about women living⇔dying with a metastatic breast cancer.

Feminist Scholars of the Material Turn who have Informed My Thinking

There are four theorists, within material feminisms where I locate my work, who have come to inform my thinking in this research project: Stacy Alaimo, Karen Barad, Susan Hekman, and Rosi Braidotti.

First, Stacy Alaimo taught me to reimagine women as embedded in their environment. Alaimo's (2008, 2012) material feminism engages with a relational conceptualization of *environment*. She works within the environmental humanities and eco-criticism and argues that nature needs to be placed in the middle of critical scholarship. From her work, I learned just how much *all* types of environments matter. In my project, it is social environs, not just multiple sets of social relations, that are of particular importance when thinking about subjectivity.

Second, Karen Barad challenged me to think differently about agency and how subjectivities are produced. At the heart of her reimagining of matter is the claims that the world we live in is one where agency far exceeds the domain of humans (Barad, 2007). Within an agentic world, reality can no longer be tidy nor linear, nor read or experienced through a set of normative constructions. For Barad, subjectivity is about re-evaluating the roles of discourse and materiality in the formation of subjects. Barad (2003) developed her theory out of an interest in having "an understanding of precisely how discursive practices produce material bodies" (p. 808). Subjects emerge through *enactments*, which have both material and discursive elements. These elements are entangled with each other, not separate entities. Her conversation on power focuses on how power is produced through these entanglements. Barad reinforces for me the idea that language does not singularly determine subjectivity and that our world is brimming with matter.

Third, Susan Hekman (2010) showed me how to embrace a process-oriented ontology in feminism through her practice of *disclosure*. Her project, a feminist renewal of Foucault, emphasizes the Foucauldian notion that the material and the discursive are not separable: "in all his writings, the interface between the two is the ground of the analysis"

(p. 60). The task is to figure out how complex forces, such as bodies and history, construct things like reality and subjecthood. To resist privileging either discourse or materiality, Hekman (2008) advises replacing "a view of language as constituting reality to one that defines this relationship in terms of disclosure" (p. 11). Here she puts Pickering's (1995) *mangle* to work as a way to emphasize the entangled interactions of discourse and materiality. These actions are not discrete. They are relational. Disclosure for Hekman is to think about how material and discursive elements, in being mixed up together, influence each other. Here the analytical power is in its *impurity,* where disclosure is a simultaneous acknowledgment of the real world and the discourses available to make sense of it. In thinking with disclosure, Hekman (2010) positions the mangle as a feminist analytical tool to capture "embodied humans living a social existence" (p. 86). For my project, with Hekman, I can critique how "the linguistic, social, political, and biological are inseparable" (p. 25) for women living⇔dying with MBC.

Fourth, and finally, Rosi Braidotti offered me practical yet expansive ways to think anew about living in an ill body and living in a world that is generatively more than human. Her work brings all my other readings together with her framing of subjectivity, discussions on the degree that our present is technology-mediated, and thoughts on what I term, living⇔dying. I first positioned Braidotti's work as a means to trouble my habits of thought and as a source of category-destabilizing reimaginings of living⇔dying. I leaned into her work on embodiment, the body and life with pain, yet was reluctant to apply Braidotti's theory to a health-related topic. However, early enough in my research, in 2015, I had the rare opportunity to attend a full-day workshop with Braidotti in Vancouver, British Columbia. From interacting with Braidotti and a community of students with affiliated interests, I learned how her contemporary work is a *practical philosophy* — which meant it would relate to my research interests. I acted on this realization by attending three theory intensive courses taught by Braidotti at the University of Utrecht, each focused on her current theorizing on relational materialism. I understand her work as a theory that *needs* to be applied. It is theory paradoxically grounded in registers of life by the very scholarship that could make her approach seem too abstract for anything practical. For my project, Braidotti (2018) offers a critique that comes out of *transdisciplinary knowledge* (p. 31) and is a compassionate response to the effects of the technologically mediated world we live (and die) in today, particularly in relation to living⇔dying with MBC.

These feminist theorists inform how and why I am using relational materialism to describe my approach. This phrase best depicts my central interests, conceptually and analytically. With the emerging nature of all material⇔discursive theories, there is no consensus on the best label for approaches that appear to be much needed (Jackson & Mazzei, 2012). Relational materialism fits well with my research goals. It foregrounds (1) the *situatedness* of women's lives in that they are suspended between living and dying, and (2) the *interrelatedness* of the women's material bodies, MBC as a disease process and the 'talk' of both. Further, my inquiry is not specific to a posthuman *philosophy* project, such as those within the humanities, wherein much of the work is located. Instead, relational materialism permits me as an engaged social worker and a researcher to *apply* a critical posthumanism.

Engaging Relational Materiality in My Project

Using relational materialism in my project means applying Braidotti's generative critique within an affirmative politics or ethics. The two are entangled threads that put into practice Braidotti's practical philosophy. These threads assist me in my inquiry on living⇔dying and producing ways for talking about MBC today.

A Politics and Ethics

Central to Braidotti's relational brand of materialism is an *affirmative* politics or ethics. Affirmation for Braidotti (2011b) is "the belief that negative affects can be transformed" into positive ones (p. 288). She purposefully recoils from theories rooted in negativity, including those where otherness is delineated by limitations and difference is grounded in lack. She seeks to shift the orientation of energies and analytical focus by "introducing movement, process, becomings" whereby a "negative charge can be transposed" or a negative passion can be neutralized (p. 288). For example, loss or grief is reimagined as "multiple forms of belonging and complex allegiances" (Braidotti, 2011b, p. 288) rather than as a singular emotional response. Thus, through the losses and grief that one encounters, the relational capacity for connecting with self and others can be nurtured.

This affirmation as part of Braidotti's politics and involves an unwavering conviction in possibilities. She strives for the cultivation of sustainable futures and recasts hope as a means of dreaming those futures. For instance, Braidotti (2011b) suggests we can look for "ways in which otherness prompts, mobilizes, and allows for flows of affirmation of values and forces that are not yet sustained by the current conditions" (p. 305). Otherness is not divisiveness. It is degrees of difference that, in part, indicate complexity and suggest what could be. Braidotti (2017) offers the salvo: that we are in this world together while holding acknowledgement, we are not all the same. Braidotti (2013) advocates for “an enlarged sense of inter-connection between self and others … by removing the obstacle of self-centered individualism” (p. 49).

Braidotti’s affirmative politics and ethics as applied in empirical research functions in two particular ways. First, having an affirmative framing allows accounting for the impersonal forces of life that exceed the human. This framing also speaks to the act of mediating the elements comprising humanity, including registers of pain. Such a framing allows me to speak to an expansive range of life forces that comprise MBC, *as* MBC is bodily known by the women living with it. What can be known includes bodily signs that may or may not be side-effects of treatment, ageing, or disease progression. No matter what the sign is, the sign is always about embodied living⇔dying arising from things like the healthcare protocols that shape women’s care and all the underlying things that make the cancer what it is: a cancer that is never still.

Second, Braidotti’s affirmative framing supports the relational aspects of language. In my inquiry, I can find ways to discuss MBC that tease, tug at, and reimagine static biomedical understandings of disease progression. This relationality already holds within it an impetus to go beyond the bodily focus of diagnosis and treatment that dominates the ‘talk’ of MBC, toward those social relations within and outside biomedicine that set up the context for women living⇔dying with MBC.

Critique

Although Braidotti’s is a *critical* brand of relational materialism, she is careful to offer a kind of critique that does not diminish, mitigate, or undermine her commitment to an affirmative politics. Braidotti (2011b) directs attention to the *thinking* part, rather than the destructive part of critique. Her work challenges researchers to consider how to practice critique, as a crucial dimension of critical thinking, that is specific to current times and concerns. This practical side of her materialism means that critique is of no use if it does not apply to everyday life.

Braidotti engages the long-standing philosophical dilemma of how to work towards desirable futures, while also being critical of forces at work today. To work with a theory that is critical, is to court the risk of 'acidity,' as in, a kind of inaccessibility from being overly critical (Haraway, 2016b). Addressing such risk, Braidotti (2017) positions critique as multi-faceted: carrying out critical commentary *while* engaging creativity. For her, critical thinking braided with creativity makes for an imminently practical philosophy. In this way, critique breaks away from revolving on an axis of opposition or seeking sharp angles of resistance (Braidotti, 2013), and moves toward some other possibility, one that is not tied to the limited options available only as part of rejecting the present.

Working with Braidotti's notion of critique, in my inquiry, I can engage voices from the margins along with embodied hopes. She offers critique as a means to engage the present affirmatively (Braidotti, 2011b). Engaging voices from the margins supported me to craft my research as something that can connect to those lost voices of breast cancer outside of the pink haze of survivorship, and with voices of those who bodily know MBC, as *otherwise*, outside of conventional framings such as terminal. Working in such an affirmative way also means liberating the notion of hope from the normative narrative of cancer survivorship and connecting with how women go about the day-to-day while living with the knowledge of a future that may be unclear, yet they know is truncated.

Putting a Relational Materialist Approach to Work: Engaging Braidotti's Contemporary Reimagining of Subjectivity

For Braidotti, subjectivity is the heart of her work, and for her, the subject has always been relational. Braidotti (2013) rejects a unitary subject and proposes a *nomadic* one where there is "an enlarged sense of inter-connection between self and others" (p. 49). Braidotti's approach is a treatise for moving beyond individualism to engage a messy more-than-human world and to understand difference as marked by degree instead of exclusion. For Braidotti (2013), her relational subject is "framed by embodiment ... empathy, and desire as core qualities" (p. 26). To think with Braidotti is to engage unquantifiable materialities of subjects that are rooted in the acutely real flow of the here and now.

Given that I am interested in the lives of women with MBC as a contemporary example of living⇔dying, nomadic subjectivity is only part of the framing for my project. Building on nomadic subjectivity, the relational materialist worldview of Braidotti's posthuman work (Braidotti 2017, 2013) is the best fit. Thus, I work with the relational subject, that is part of her posthuman framing of contemporary society as one of rapid technological innovation and part of teasing out materialities in a posthuman landscape. The relational subject in this project is my brand of a posthuman subject.

The relational subject Braidotti (2013) puts into analytical play is infused with her reimagining of Deleuze's concept of *desire.* Braidotti rejects desire as stemming from lack, and in doing so, disconnects desire from negativity. She is adamant that desire is about ontological passions that fuel movement toward a subject; that is, fuels becoming. Desire is about processes *to be* and *to become*, instead of about seeking what is not present. A theme in Braidotti's (2011b) work on desire is that it is a striving to connect with something that gets us going in this life. This type of striving is not directed and is not to be confused with striving as a state of mind, or any other normative framing. Within a relational subject, striving is an embodied capacity to open to forces of the broader world in ways to permit possibilities to emerge. Such becoming 'all-one-could-be' is a vortex of both desire for transformations and for encounter with real-world tensions. Desire provides a basis upon which Braidotti can place the relationality of her (posthuman) subjectivity. For this project, thinking about subjectivity relationally, permits me to think through the practicalities of living⇔dying as desiring acts of connection on the path to becoming.

With desire, it is necessary to add that Braidotti (2011b, 2013) calls for the recognition of what is 'truly' desire, given the ever-present pull of consumerism today. In my project, health diagnostic and treatment services and healthcare provision cannot be exempt from this pull. Desire in the way that I talk about it, following Braidotti, is distinguished by its generativity. That is, not the craving affiliated with the dissatisfaction that is the offspring of commercial agendas, and corresponding actions of customer service, healthcare, and even well-being. Instead of the ache of longing and absence characterized by a desire based on lack, Braidotti (2013) talks about recognizing desire through its "electro-magnetic charge" (p. 134). A charge that excites and pushes people to connect with one another and with different things.

Interlaced with the ontological passions detailed above, my approach entails a willingness to stay with the potentially uncomfortable aspects of subject formation that are found in the present (Braidotti, 2013, 2019), particularly so with critique. In this sense, any project grounded in real-world situations ensures an ethical accountability to the present

(Braidotti, 2011b, 2013). There is a daring to be in the here and now, and fighting for whom we might become (Braidotti, 2010a, 2013). Such a stance takes the form of a particular type of hope. One that moves toward acts that are thus far unrealized. These acts also have within them associated tasks that never lose sight of sustainable futures. Part of the daring in my work as I explore relational subjectivity is to sit with whatever I might find in embodied terrains of an advanced, but not explicitly advancing, cancer.

With Braidotti's use of relationality, within her notion of subjectivity, there is also an exploration of alternative modes of subjecthood specific to living with a "spectacular body-threat" (Braidotti, 2017, p, 113). Braidotti has written extensively about death, even offering a posthuman theory of death. She brings life, death, and dying into a reimagined materiality that spans the movement of living and dying. Speaking specifically to the bio-mediated world today, Braidotti draws attention to how boundaries of living and dying are changing (as discussed in Chapter 1), by pinpointing "new and subtler degrees of death" (2013, p. 115). She covers diverse social contexts, including medicine, to map how to sustain a compassionate commitment to the *embodied self* while encountering dying. Such an understanding of relational subjectivity in dying opens up expansive possibilities for my project. Braidotti (2011b) locates death as no longer contained *within* a person. She frames death as yet another generative and relational process. It is part of the flow and the forces of Life where dying generates something else in its wake. Braidotti provides a way to dismantle the mainstream focus on death as 'degrees of subtraction' specific to an individual, typically in terms of loss (of self), grief (over that loss), and absence (of that which one once had). For my project, this conceptualization of dying allows me to think of the effects of dying as "how contemporary embodied subjects are interacting" (Braidotti, 2017, p. 130). In this way MBC, as a research interest, is no longer constrained to categorizations and subjects such as the individual cancer patient, the cancer survivor, or the client who has an incurable disease. Instead, I can look to other subjectivities that might emerge through the women's experiences.

Overall, in my project, I engage ideas at the intersection of Braidotti's account of her relational subjectivity and her posthuman understanding of dying. I use this framework so that I can think in the boundaries of living and dying and focus on the emergence of a particular subject.

Thinking With Relationality in Subjectivity for My Inquiry of Suspended MBC as Living⇔Dying

Jackson and Mazzei (2012) provide guidance on selecting concepts, principles, and/or figurations for a critically informed qualitative inquiry. They describe how they selected "concepts that would help us to extend our thinking beyond an easy sense" (p. 7). Inquiry is not to rest with the easily accessed, readily received, or generally accepted knowledge. Instead, to engage inquiry is to be "the wayfarer" (Haraway, 2016a, p. 36), one who is aware of one's entanglement in a more-than-human world. As wayfarer, the researcher finds ways through the entanglement by accepting "collective responsibility" of our times (Braidotti, 2006). As part of my relational materialist approach, using this type of posthuman thinking allows me to use concepts to *disclose* what is going on, rather than trying to determine what is going on. In other words, disclosure is a different project than attempting to grasp an objective truth that is out in the world waiting to be found.

In selecting concepts appropriate to my relational materialist project, I learned that it is *processes* that are significant (Jackson & Mazzei, 2012). For concept selection, the researcher may begin by considering particular concepts. However, as concepts are framed more like pliable thresholds than prefabricated tools, analysis is not about applying them by rote. Concept selection is about thinking about how the concept works and how the concept is a launching point for further thinking.

Keeping Jackson and Mazzei's work in mind, I turned to concepts that I could use to animate the relations and subjectivities of the women in my project. I ruled out feminist poststructural concepts that were not part of the ontological turn. I considered concepts across the spectrum of what Coole and Frost (2010) call the *new materialisms*, with an acknowledgment that not all of these fit with a feminist or relational materialist framing. I considered concepts within writings that can be considered relational materialist. For example, a particularly informative and generative resource was the interdisciplinary posthuman glossary project (Braidotti & Hlavajova, 2018). I also found it informative to consider how a guiding question in their choice of concepts was: "what methodological and political alliances might we envision in order to co-create conceptual and experimental terminologies pertinent to the complexity of our time?" (BAK, 2015, para. 2). With this sentiment in mind, I also consulted critical posthumanist sources that I deemed to be compatible with my relational materialist approach. I also considered literature specific to living⇔dying, such as those discussing necropolitics.

I came to realize that thinking through a particular framing of contemporary subjectivity could work. Subjectivity is connected with a key interest: whom did women find themselves to be over time, and along the way? I would look for subjectivities across registers of fit that include (widely) available social identities and medical categorizations. Building on these Foucault-inspired thoughts, I sought how specifically to put to work subjectivity as a concept for my particular project. At the core of my theoretical framework is a framing of a relational subject, informed by a posthuman understanding of dying, one that I did not pull out of the literature, pre-formed. Given the intricacies at play with both my research question and the sphere of potential participants, I assembled a theoretical framework informed by three interconnected principles.

Principles Informing Subjectivity

A working caveat for relational materialist empirical inquiry is that it matters how principles are put to work, for the questions we ask, change, if we use different principles (Braidotti, 2011b). The principles I put to work in my project are feminist. They are more egalitarian than rational, along with being a way to make moral choices and to develop analyses up to the complexities of our times (Braidotti, 2002, 2011b, 2019). In other words, principles can be discursive strategies and be part of structuring critique. It was from lectures with Braidotti that I learned how to take up principles in empirical inquiry so that I could think differently and/or open up lines of inquiry. Each of the principles I will discuss resonates with the framework of relational materialism that I laid out above. To this end, I chose three principles that collectively activated possibilities for those just big enough stories of living⇔dying with MBC: being relational (becoming), embracing *Life* (embodiment), and holding complexity (materialities).

Being relational. Being relational is a primary premise of my relational materialist theoretical framework. Being relational means opening up possibilities of understanding how women with MBC come to mediate the technologies available to them and make decisions about their illness, and how women manage aspects of their lives where illness does not figure prominently. Disease progression in MBC has traditionally been the dominant way that biomedicine encounters and deals with women's bodies. These bodies become an active site of medicalized knowledge and practices arising from that knowledge. Being relational means thinking with the process of becoming as part of ontological positivity, the generative force that creates subjects. In my project being relational helps to disclose the processes that generate the subject *in situ* (Braidotti, 2017). Within modes of becoming, 'what something is' is more than merely the connection between any two points, things, or entities (Jackson & Mazzei, 2012). Instead, 'what something is' is about how multiple "points, things and entities" come together in the generation of a subject. This "coming together," occurs "through the flesh, in embodied locations and not in a flight away from them" (Braidotti, 2002, p. 23). This generative process is relational, connected to many things, and is an unpatterned zigzag, never travelling in a straight line. Propelled by forces of becoming, the subject is thus a trans-individual made up of complex relationships and is among elements that contribute to how we think about the subject as a whole. In this sense, becoming does not adhere to stable notions of sameness. Thus, relying on identity as the marker of women living⇔dying with MBC is fraught with the problem of reducing individuals to a single entity, that of an illness.

Being relational is to think of desire as a productive force in the generation of subjectivity. With becoming, "desire is the propelling and compelling force that is driven by self-affirmation or the transformation of negative into positive passions" (Braidotti, 2011b, p. 154). The negative is that which holds back, thwarts, and cuts off the flow of desire. Conversely, the positive is that which facilitates, enables, and smooths out the flow of desire. The direction of the flow of desire is not important: "becoming is an intransitive process: it's not about becoming anything in particular — only what one is capable of and attracted to and capable of becoming" (Braidotti, 2011b, p. 313). The principle of being relational permits a subject to be an embodied actualization of desire, one of plenitude (not lack) and multiplicity (not singular).

Jackson and Mazzei's (2012) *desiring subject* was an inspiration for my nascent sketch of the relational subject. Informed by relational processes of becoming their application of the desiring subject is an explicit break with the humanist subject. For Jackson and Mazzei, analysis does not focus on the emergence of any one subject. Instead, they focus on how "subjectivity is becoming with each experience, each telling, each desiring" (p. 93). Jackson and Mazzei use *desiring machines* as a way to mark the circulation of desire. The purpose of research is to trace how these machines plug into each other, then produce even more (and different) becomings. In my project, the subject as the effect of the circulation of desire is to simultaneously think about those with MBC as both producing and being produced through the relational process of becoming. These ideas can assist me in addressing how desire works through and within the women's lives replete with multiple sets of connection among "points, things and entities" (Braidotti 2002 p. 23).

Embracing Life. As noted in Chapter 2, the topic of my research has traditionally been bounded by biomedical parameters around what constitutes life-limiting illness. For this project, I seek to expand these parameters. Life as *zoe,* or simply Life, incorporates a wider scope of bio-political concerns (Coole & Frost, 2010, p. 203). Inseparable from Braidotti's ideas about affirmation, zoe is a generative life-force of the kind that "carries on regardless" of human control (Braidotti, 2011b, p. 113). Zoe signals the idea that life can, and does, extend beyond a static, human-centric framing (Braidotti, 2010a). Biomedicine tends to view life in terms of functioning tissues, cells, and systems. However, embracing life takes into account life-forces and processes of becoming that exceed the more readily accessible matter.

Life as *zoe* reinvigorates debates of embodiment and body. Braidotti (1994, 2011b), frames the body as exceeding representation and casts embodiment as flows of energy. The relational subject, too, is embodied. Thus, there is no enclosed internal landscape consisting of subjective experience or reflection of the body. Instead, the relational, embodied subject is "a folding in of external influences and a simultaneous unfolding outwards of affects" (Braidotti, 2006, p. 159). Much like Braidotti, I want to embrace Life. So, for this project, I too set the task of "how to rethink the body in terms that are neither biological or sociological" (Braidotti, 1989, p. 98).

With zoe, the body is vibrant agentic matter and the basis of a relational and embodied subjectivity. Thus, an aspect of the analytical strength of embracing life, as part of accessing the subjectivities of women living⇔dying, is the opening up of possibilities to the question of what a body can do (Braidotti, 2006, 2019). This is different than presuming that we know what a body can do. Women living⇔dying with MBC cannot strictly be framed by biomedical categories. For example, cancer as demarked by designated stages of progression or by a standardized illness trajectory. My project seeks to disclose marginalized embodied subjectivities. These exist outside of healthy, functioning bodies, “being zoomorphic, disabled, malformed or ill-functioning [that] are pathologized and classified on the other side of normality” (Braidotti, 2002, p. 123). Each woman exceeds such human-centric categories because she is in relation to the many things that make up the illness. These include diagnostic protocols, treatment regimens, disease processes, support networks, family relationships, and the women’s personal histories. Embracing Life, then, is a relational materialist principle that, when used for analysis, offers more accuracy of “the complexities of contemporary technology mediated bodies and on social practice of human embodiment” (Coole & Frost, 2010, p. 203). Working to disclose these multiple modes of embodiment through embracing life, I can address that curious space of in-between living⇔dying with MBC. In so doing, maybe figure out how subjects come to emerge in this context.

Holding complexity. In addition to being relational and embracing life, I seek to hold complexity in the “entangled production of subjectivity” (Jackson & Mazzei, 2012, p. 119). Although not entirely separate from the other two principles, holding complexity is a significant conceptual strategy to respect how the processes of becoming exceed the individual. A means to embrace Life, going beyond physical bodily constraints. Like Hekman’s (2010) use of the mangle, which is a way to speak of material⇔discursive processes, I do not want simply to reassert materiality into my inquiry. My focus is on the entanglements within a daily world that is presumed to be agentic, much like a humming hive of energies and forces (Braidotti, 2002). Conveying the complexity of the analysis — conceptually, analytically, and empirically — is a challenge. Yet, I still endeavour to hold complexity of the relations among entities.

Exceeding framings of cause and effect, in holding complexity, I direct my analytical attention to poly-enactments of subjectivity that shift in light of the intra-actions of the entanglement of zoe, society, and technology. In this way, holding complexity is putting to work *intra-activity* (Barad, 2007) and *relationality* (Braidotti, 2011b). Intra-activity involves the back-and-forth generative process located at the interface of discourse and materiality. Here neither discourse nor materiality dominates or determines the other (Barad, 2007). That space where intra-activity occurs brings into focus various dimensions of becoming. Thereby, allowing engagement with more complex relations and aspects among points, things, and entities that demand analytical attention. When not privileging either biology over the cultural, or the material over the discursive, both become central to the analysis.

With subjectivity, it is helpful to think of intra-activity as 'points of contact' in a world of materialities and subject positions. Subjectivities are constantly being made and unmade through intra-actions between points, things, and entities (both human and non-human agentic forces). For my project, holding complexity means bearing in mind the complex terrain that women living⇔dying with MBC traverse on an ongoing basis, as well as the complex analytical framework of relational materialism and all that it entails. Points of contact in this project include things like policies, treatment regimens, and bodies with MBC. They also include adapting protocols to individual bodies, getting to the clinic for appointments as needed and monitoring seemingly benign bodily functions. Within points of contact, I must also conceptually avoid the ensnarement into the subject/object dichotomy.

Working Analytically with Relational Subject as a Living⇔Dying Subject

Helping to sustain the relational subject as living⇔dying, is the principle of zoe that is "unconcerned by clear-cut distinctions between living and dying" (Coole & Frost, 2010, p. 203). With the use of zoe as a "relentlessly generative force" (Braidotti, 2013, p. 121), I am contesting the normative dichotomy of life and death. I am disrupting a human-centric framing of death. Life is one where we as humans do not have jurisdiction over death; we only occupy a "time-share" (Braidotti, 2013, p. 133). Using zoe introduces an analytical flexibility in thinking about the day-to-day in terms of relational, embodied subjects, and Life. For example, the imposition of sorting ambiguous phases of living and dying into the fixed categories of remission, stage, or terminal status only reduces the women to a fixed notion of a diseased body. This process concurrently wreaks havoc on the women's psychological and emotional lives, and those close to them, as they cling to the edges of each category. Working with a living⇔dying subject in my project, I may be able to speak to the subtle and complex ways that women live and die.

By thinking in terms of a subject as living⇔dying, there is capacity for analysis of how emerging terrains of technologically-mediated life shape how women take up living with MBC and how the boundaries of flesh and machine are blurring. Given how the living⇔dying subject is also a desiring subject, I can emphasize relational forces of living⇔dying that are often subtle, salient, or unseen in the lives of women who have relatively stable forms of MBC. Such a critique covering a wide scope of registers of Life is not only generative, it is affirmative. Analysis considers registers that are socially difficult to discuss, but that can have a significant impact on those living with life-limiting illness. These registers include the joyful, the bittersweet, and the horrific. As well, the desiring subject holds potential. If there is desire, then there is also the possibility of another desiring, another seeking, another desire, and so on. Because desiring subject is a generative aspect of becoming, I can better track the shifting permutations of living and dying for the women with ongoing MBC.

Conclusion

In this chapter, I discussed how my goal of generative inquiry into the lives of women who are living⇔dying with MBC led me to develop a relational materialist theoretical framework informed by posthuman understandings of the subject. I use a relational materialist approach to understand the processes through which subjects are generated. Rather than being bound by the concept of posthuman subject, my use of principles distinguishes my brand of a relational subject. This theoretical framework, and its related concepts and principles, guides my reading and presentation of the empirical part of this study. I also use this framework and set of principles in the design of my project. In the next chapter, I discuss how I apply these ideas in the methodological considerations and the research design.

Chapter 4: Methodological Considerations and Research Design

Choose one set of tracks and track a hare
Until the prints stop, just like that, in snow.
End of the line. Smooth drifts. Where did she go?

Back on her tracks, of course, then took a spring
Yards off to the side; clean break; no scent or sign.
She landed in her form and ate the snow.

Consider too the ancient hieroglyph
Of 'hare and zigzag', which meant 'to exist',
To be on the *qui vive*, weaving and dodging

— Seamus Heaney (1991, p. 97)

I designed this research project in response to gaps both in the literature and in healthcare service practice that I knew existed from both personal and professional experience. For my dissertation, I chose to conduct a qualitative inquiry, informed by a set of methodological principles drawn from the entwinement of *thinking with theory* approach for qualitative research and Braidotti's feminist brand of relational materialist theory. Drawing primarily from Jackson and Mazzei (2012), I made use of the analytical processes of *decentering, zigzagging*, *diffraction,* and *writing as inquiry* (for further details see pp. 114-121). With sensitivity to post qualitative inquiry research principles as introduced in Chapter 3 (e.g., Lather & St. Pierre, 2013; Jackson & Mazzei, 2012; St. Pierre, 2011), I used multiple data collection methods: primary participant interviews, cluster interviews (the phrase "cluster interviews" comes from my co-supervisor Dr. Kelli Stajduhar; this was a cluster of people identified by a primary participant who, through individual interviews, could add in-depth understanding of life with MBC), key informant interviews, and review of significant documents. In total, I spoke with 28 interviewees (42 interviews total) and collected 27 documents (see Table 4.1).

Table 4.1 Summary of Data Sources

Data Source	Number	Notes
Interviewees	28	Primary participant interviews, cluster interviews, and key informant interviews.
Women with MBC	14	These are the project's primary participants. 2 interviews each, plus a follow-up telephone call.
Cluster interview participants	10	3 clusters total: one with 3 members, one with 4 members, and one with 3 members.
Key informant participants	4	1 was a general practitioner working in a smaller community. 1 was an internal medicine specialist. 1 was an academic and researcher in the cancer field. 1 was a community educator in women's health, including breast cancer.
Documents	27	3 were materials produced by pharmaceutical companies. 3 were downloaded from Island Health Authority. 12 were from the BC Cancer Agency. 6 were from social media. 2 were from newspapers or online equivalent. 1 was a mass-market book.

For data analysis, I used theory to inform my reading of the data so that I would get "out of the representational trap of trying to figure out what the participants" in my project 'meant' (Jackson & Mazzei, 2012, p. viii). I hoped to "critique the complexities of social life"

(p. vii). I see analysis as a process of working to “exhaust” (p. ix) my inquiry into the material⇔discursive threads of subjectivity and the effects on daily life as recorded in the texts. Ethical practices for my inquiry included formal ethics, politically-informed ethics, and research project integrity. Ethical practices comply with the University of Victoria research ethics and an extended set of political ethics (Braidotti, 2011b, 2013), with consideration of a social work code of ethics (British Columbia Association of Social Workers, 2019).

Grounding my methodological work is the research question for this project. As introduced in Chapter 2, the question is: how are women, who are living with MBC as a life-limiting illness over an extended period, produced as both living and dying subjects?

a) How do permutations of uncertainty contribute to the materialization of these women as subjects who are both living and dying simultaneously?
b) How do women with an ongoing form of MBC mediate the resources available to them in their everyday lives?

This chapter is divided into two parts. In the first part of this chapter, I set out the methodological considerations for this project. I first discuss the methodological principles that reflect the purpose of the project. Then I turn to a discussion of ethics, including formal ethics and politically-informed ethics. In the second part of the chapter, I set out the elements of the research design. I provide data collection methods, including primary participant interviews. I then describe how I systematically engaged the analytical methods. Here, I detail the analysis processes, introduced at the start of this chapter, and the data analysis practices.

Methodological Considerations

Key methodological considerations for this project were methodological principles and ethical practices. These methodological considerations laid the groundwork for the research design.

Principles

My methodological principles reflect the purpose of my project, working to address the need for more, and reimagined, research of MBC as a life-limiting illness today. In the early 2000s, Tritter and Calnan (2002) emphasized that more research was needed to "understand the tensions between acute and chronic aspects of cancer" (p. 164). Since the early 2000s, the need for such research has amplified. My research project addresses this need by focusing on "the language, the categories, and the stories" (Lynn, 2005, S14) of those with "a prolonged trajectory of dying" (Nissim et al., 2012, p. 385). Within this research, I follow Hekman's (2010) argument that feminists cannot afford to ignore the material world for there is "the necessity of making true statements about the reality of women's lives — their oppression, their inferior social status, the pain inflicted on their bodies" (p. 66). For the research design, I needed to consider how to support my goal of troubling the production of simplified understandings of daily life and staying with the messy permutations of living⇔dying.

I carefully considered the stories that different research designs (e.g., grounded theory and feminist ethnography) would be able to tell and the ones they would not. The process of designing this research project propelled me away from selecting a conventional qualitative design with the goal of describing experiences of daily life or providing snapshots of experience. Instead, an inquiry that would offer an analysis of how those experiences comprising daily life are socially produced. I read widely, not limiting myself to the training of either my research background in medical psychology or my more recent studies in poststructural feminism. I revisited 'methodology' and how the starting place for inquiry might not be a set of pre-existing methodologies or designs by thinking intensively about theory (St. Pierre, 2011, 2015). The theory could help me figure out how to 'do' inquiry given my project goals, thereby troubling limitations of conventional research designs (St. Pierre, 2015). From here, I considered how revitalized thinking on epistemology and ontology 'together' in qualitative research "might allow [me] to apprehend worlds in new ways and to build new ways of living and being" (McCoy, 2012, p. 762). Furthermore, I looked forward to "interventions that might become possible by opening up to more complex practices of qualitative research" (McCoy, 2012, p. 763). I drew analytical cues for methodological action from Jackson and Mazzei's (2012) strategy of thinking with theory and concepts across the data because it brings "thinking methodologically and philosophically together" to produce knowledge with critical consideration of materialities (Jackson & Mazzei, 2012, p. vii).

For my project's research design, I framed the empirical inquiry by relational materialism (q.v. 2006, 2011, 2013; see Chapter 3). In this way, my research process could be characterized by "a methodology that focuses on processes and interconnections" (Braidotti, 2010a, p. 206). In addition to being relational, this kind of empirical inquiry is grounded in bodily accounts here and now. In particular:

> I am seeking modes of representation and forms of accountability that are adequate to the complexities of the real-life world I am living in. I want to think about what and where I live — not in a flight away from the embodied and embedded locations which I happen to inhabit. (Braidotti, 2006, p. 7)

For empirical inquiry, this is a constructive way to step back from the framing of MBC as a well-delineated or at least well-understood disease in the biomedical terrain I inhabit as a social worker and social scientist. Throughout my research, I sought clues that suggest how MBC may be a life-limiting illness in significant transition. Thus, I think about MBC as something that is concurrently known, unknown, and unknowable. It is these post qualitative streams of feminist thought — where things can be known, unknown, and unknowable at the same time — that enhance the analytical and empirical possibilities for my work. They are dynamic pathways to explore emergent realities of day-to-day life with living⇔dying and with them shifting subjectivities.

Part of the appeal of relational materialist empirical inquiry is that it rests upon a critique of the praxis of power and affirmation. With acknowledgment to Foucault, but also drawing from Deleuze, power is rendered neither negative nor positive (Braidotti, 2011b). Inquiry includes tracking effects of *potentia* (enabling/empowering energy) and *potestas* (restrictive/disempowering energy). Potentia is a force relation that can enable people to do things and potestas sets up boundaries that can limit what people can do. This pushing-pulling, or being restricted in some ways and trying to generate some potential in others, is a process of becoming that Braidotti's critique is tailored for. The ways in which women living⇔dying with MBC navigate both potentia and potestas shows how they carve out lives they find affirming, ones that differ from those offered to them through biomedical discourses of MBC. Thus, I can more fully satisfy my empirical goal to conduct research capable of disclosing intensities, uncertainties, and complexities of living with a suspended life-limiting illness.

Ethics

Ethical practices included formal ethics, politically-informed ethics, and research project integrity (See Table 4.2 for a brief description of each). I obtained formal ethics approval through the University of Victoria Research Ethics Board (see Appendix B). I am also committed to a feminist relational materialist ethics in research: an ethics that guides me as to what it means to be in compassionate relationship with the women and the family members I spoke with. I maintained project integrity through the practices of researcher embeddedness and awareness of project limitations. I now turn to describe each in more detail.

Table 4.2 Ethics

Ethical Practices	Details
Formal Ethics	Met requirements for human research ethics approval through the University of Victoria Research Ethics Board.
Politically-Informed Ethics	Committed to a feminist relational material ethics for ethical decision making, including applying sustainability (Braidotti, 2006, 2010a) and taking responsibility and accountability for the material consequences of human action (Hekman, 2010).
Research Design Integrity	Worked with feminist relational material theory to disclose researcher embeddedness and to address project limitations.

Formal ethics. I obtained approval to conduct this project from the Research Ethics Review Committee of the University of Victoria. Participation in this project was voluntary. All participants were sent a copy of the consent form before meeting with me and were invited to reflect further on whether they wanted to participate (see Appendices C, D, E, and F). With all participants, at the start of the first interview, I discussed confidentiality (including limitations) and I obtained informed consent. To ensure ethics were upheld, with participants who had more than one interview, I revisited confidentiality across subsequent interviews.

Politically-informed ethics. A touchstone I used for ethical decision making in this project was a relational materialist framing of *sustainability* (Braidotti, 2006, 2010a). Sustainability is having a heightened sense of the interrelationships that the self has with others, both human and otherwise. In being ethical, there is an assured rejection of a *unitary subject* or an individual presented without the social processes they are embedded within and that have shaped them. In my project, sustainability supports attunement with intensities of the day-to-day of living⇔dying and relational-ethical engagement with project participants. Sustainability is a political commitment.

Another facet of my decision-making was taking responsibility and accountability for the material consequences of human actions (Hekman, 2010), particularly mine as the researcher. I understood research practices as generative of realities rather than static tools (Law, 2004). The material⇔discursive elements I turned my critical attention to require a particular kind of care, as there was the need for “cultivating positive ethical encounters” (Braidotti, 2010a, p. 248). For instance, I took into consideration pain in its many embodied permutations (Braidotti 2010a; Hekman, 2010). With an eye towards material consequences, I worked to be immediately ethical (Hekman, 2010) or responsive to events as they unfolded, staying within the present.

An ethical tension between formal ethics and politically-informed ethics was the difference in how I, and the ethics board that approved this project, held the notion of ‘vulnerability’ of primary participants. It is widely known that women with MBC have vulnerabilities as people who have a serious illness, although what is often missing is, precisely what that means for the women themselves. There is even less understanding of vulnerability when it comes to women with suspended forms of MBC. For example, they may be individuals who are not actively unwell or dying, which is a conventional way of understanding vulnerability. I found that part of the formal ethics process was that I needed to advocate for potential participants not to be categorized in the ethics approval as *high risk*, in terms of vulnerability. I was situating vulnerability within embodied and embedded registers of women's lives. This 'vulnerability' contrasts with normative understandings centring vulnerability in regulated issues of liability which, by virtue of their construction are dissociated from women's lives. Informed by the proposed feminist ethics of this doctoral project, my advocacy efforts were successful with the ethics board.

Another ethical tension arising from the research was sustaining registers of emotion in the data. Part of a relational materialist approach in inquiry is engaging intensities of life throughout the posthuman methodological moves we may use (Braidotti, 2013). Emotional registers are part of that tapestry, but more often present in writing style than in content. In my project, data from cluster interviews offered a sense of the emotional terrain that is part of living with advanced cancer. For example, a father spoke in fragmented sentences and stuttered questions about his prolonged confusion over whether his adult daughter was dying or not. For me, as part of my sustainable ethics in this project, weaving emotional threads into findings was ethical action.

Research Project Integrity

Key actions of project integrity were researcher embeddedness and awareness of project limitations.

Researcher embeddedness. I used a theory-informed, process-oriented reflexive writing practice to disclose better how I, as the researcher, was embedded in the research (St. Pierre. 1997). I found inspiration from materialities-informed autoethnographic writing strategies, ones where 'auto' in autoethnographic does not imply an individual 'I,' but instead, an 'I' that is a register within a mangle of forces (Jackson & Mazzei, 2012, p.10) and where 'self' is of the kind that shudders in the flux of materialities of life (Braidotti, 2011b). This practice helped satisfy the post qualitative imperative of "aesthetic crafting of research as an ethical imperative of research" (Spry, 2011b, p. 498). It also supported critical reflection as a practice to make visible research as a product of enacted design (Jackson & Mazzei, 2012). Understanding my embeddedness alongside the women's was a way to disclose the processes of production and the presence of the researcher at work, including the researcher as being in intra-active entanglement with project participants.

Over the course of my project, disclosing researcher embeddedness took on a greater need because of significant shifts in how I was personally and professionally situated with life-limiting illness. My encounters with MBC and life-limiting illnesses are multifaceted and cover decades (see my discussion in Appendix A). A fundamental shift in my embeddedness came near the beginning of this project when I lived through a serious medical event, which at first was thought to be MBC (ironically), but then was found to be a different permutation of living⇔dying. This event required me to re-think how I bodily knew MBC and my place in this project.

My trajectory was akin to putting to work *living inside* (Bordo, 2008, p. 403), a writing practice that helped me to sustain project focus on participants. I could acknowledge the entanglement of my changed health status with other aspects of my life and connections with the women in the project, while ensuring this was not driving the doctoral work. This practice does not hinge on the conventional insider/outsider dichotomy as discussed in social sciences research, but on writing from the non-linear space of quite literally living inside an issue (Bordo, 2008). My 'inside-ness' with living⇔dying was not so much a site of expertise or knowing, but a site I could not have imagined beforehand (Bordo, 2008). Rather than being an assured expert, I had an embodied commitment of "moving in and out of trauma with words and blood and bone" and "dropping down out of the personal and individual to find painful and comforting connection with others in sociocultural contexts of loss and hope" (Spry, 2011b, p. 498).

Project limitations. I was aware that a limitation of this research was that empirically it was within an emerging body of literature. Just as the landscape of living with ongoing life-limiting illness often lacks definitive waymarkers and landmarks, so too did the domain of research/exploration of 'chronic life-limiting illness.' When I first started this project, there were few publications and studies. At that time, exploring ongoing life-limiting illnesses outside of AIDS was still relatively new as a research phenomenon. A corresponding strength of my project has been vigilance to the emerging empirical and theoretical landscapes, including resourcefulness in locating discussions in the margins. A further strength is being rooted in a community milieu where one could see the changing shape of life-limiting illness and the construction of the doctoral project being a situated response.

I can also speak about the same limitation regarding the theoretical literature. Critical posthumanism and relational materialism are fields now gaining traction within both the social sciences and practitioner research. For example, applying critical posthumanism in healthcare is a particularly new endeavour, most often seen thus far in parts of Europe. The status of relational materialism, as applied in healthcare, is even more nebulous. My tutoring on how to apply relational materialism as a practitioner came from Professor Braidotti through summer school intensives at the University of Utrecht in the Netherlands. My project is part of a larger conversation about the scope and the possibilities of critical posthumanism and/or relational materialist projects on healthcare-related topics, including cancer.

To strengthen project integrity, I worked with a visioning initiative that runs through a Braidotti-informed empirical inquiry: to always think to a bigger future and what your work might do. I thought about how my project might connect with future readers. What might the work of this project become, in their imaginations and in their goals for supporting women with MBC? How would the project emotionally and/or intellectually affect future readers? How else might my work be a catalyst or a kind of gravity shifting inquiry into MBC? How does my work inspire me as a researcher and healthcare practitioner to generate new questions and new lines of inquiry?

Research Design

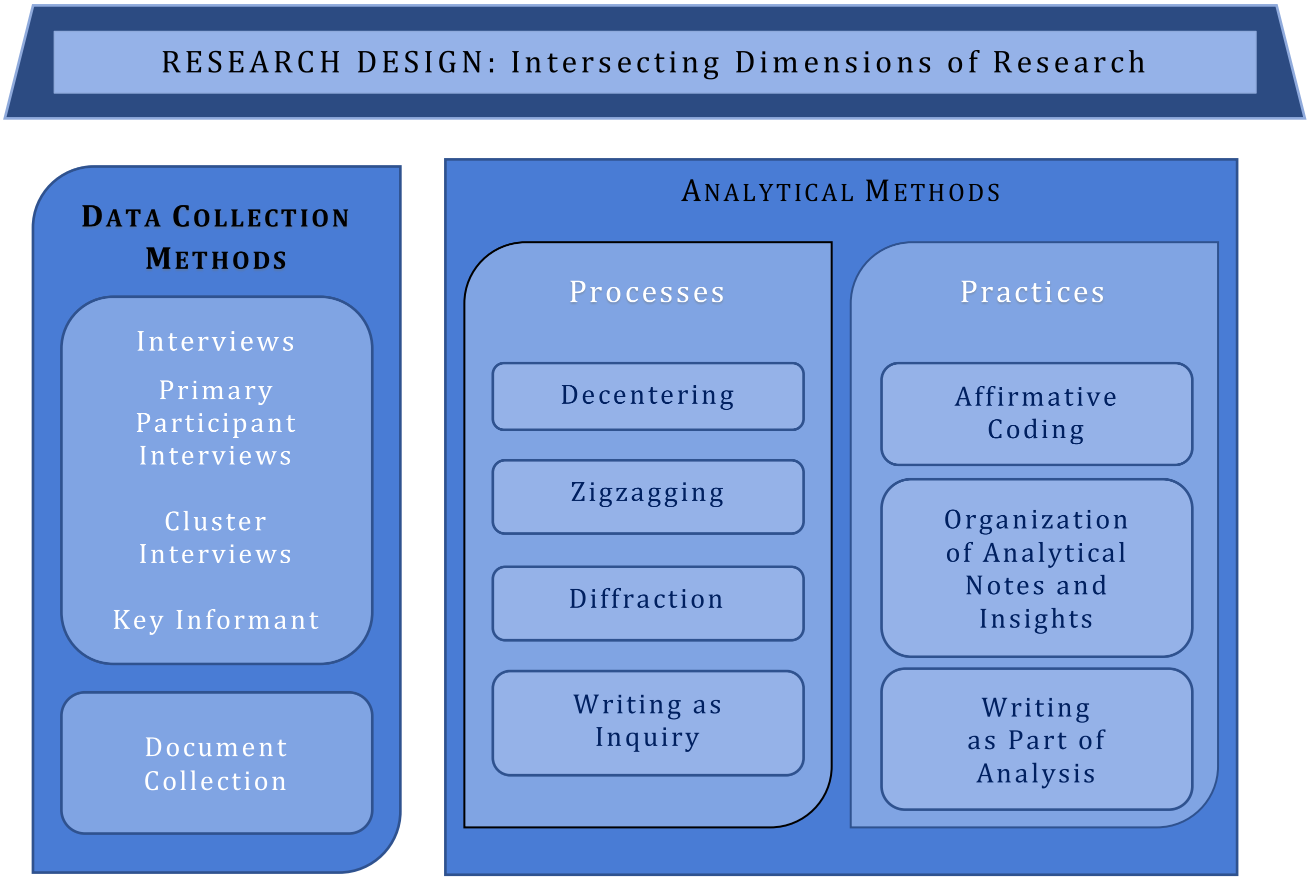
Having laid out the methodological principles that informed my choices of analysis and the ethical practices that permeated this project, I now turn to the design of the project itself. I designed a research project with two intersecting dimensions of research: data collection methods and analytical methods. I have developed a visual representation of all the parts (see Figure 4.1 and Figure 4.2).

For data collection methods, I conducted interviews and undertook a document survey. I interviewed three groups of people: primary participants, cluster interview participants, and key informants. I talked with and collected stories from 14 women with MBC. I refer to these women as the primary participants. All interviews with these women were audio-recorded. A professional transcriptionist recommended to me by a committee supervisor, then transcribed them. I also worked with a selection of primary participants to identify 3 to 4 people whom they saw as key individuals in their lives who could speak to living with MBC over time. I refer to this as cluster interviewing. I interviewed 10 people individually across 3 clusters. I conducted interviews with 4 key informants who were professionals from diverse fields and who could speak to MBC in the community. For the document survey, I located documents that disclosed discourses shaping the material realities of women living with MBC. In total, there were 27 documents.

Analytical methods in the form of data analysis processes proceeded, as I have outlined in Figure 4.1. For sorting and coding data, I managed multiple sets of shorthand notes and long written passages about addressing the questions I posed. I did not use any software. I wrote all my notes within the printed transcripts or on post-it notes spread across a large artist's storyboard. These notes were a way to make visible, emerging thoughts and questions. I used notes as tools to clarify, revise, discard, and expand my analysis.

These research dimensions, imbued with methodological considerations, were not always discernable from one another, as they overlapped temporally and/or substantively. Ethical practices permeated interviews, which could be most readily discerned with primary participants and with their loved ones. I was also aware that I attended interviews as a researcher drawing from feminist relational materialist ethics, sustaining a mix of compassion with critical analytical interest. Interviews with key informants inevitably produced more documents for me to locate and read. Sometimes it mattered that these dimensions overlapped, and sometimes it did not, an idea I will return to later in this section.

Figure 4.1 Research Design



Data Collection Methods

There were two data collection phases. The first was the phase planned for in the project proposal. I focused on interviews and follow-up with primary participants. During this phase, I started the collection of documents, see below for details. I continued collecting documents until the end of the project. The second phase grew iteratively out of the initial data collection phase. In this phase I undertook cluster interviews and key informant interviews. These methods added depth to existing data.

To address a potential methodological conflict, I want to acknowledge that interviewing is a staple of standard qualitative research, so how does this fit with my research design? Conventional social science data collection methods are suitable for producing data when applied in conjunction with thinking with theory (Jackson & Mazzei, 2012). In choosing to address this option, I conducted interviews primarily because this was a way to further situate women as the agentic center of their own stories and to lean into what practitioner-driven relational materialist inquiry within healthcare could be.

Interviews. There were three sets of interviews: primary participants, clusters, and key informants.

Primary participant interviews. There were two main factors for deciding on how many primary participants would be needed for the project. First, concomitant with post qualitative inquiry, my stance was that the actual number of participants was less important in determining project trustworthiness than the diversity and the information-richness of evidence (Morrow, 2005). Thus, my main recruitment focus was on richness and subtleties of data, not quantity. Second, I did not know beforehand how many women would be part of the project and how many would be able to complete the project, whether because of general life changes or health-specific reasons. I worked with this uncertainty that would come to permeate recruitment from the beginning of the project to its end. To invite as many participants as possible, I recruited participants from a geographic area covering several smaller communities on Central Vancouver Island and thus had to be creative in generating opportunities. Several means were used including, a type of snowball sampling method because women with suspended MBC are difficult to locate through traditional healthcare channels, and I knew that women with MBC would have connections unknown to me. Considering these two factors, the richness of evidence and uncertainties in recruitment, I set a tentative goal for between 10 and 12 primary participants.

My guiding strategy for recruiting participants was threefold: to generate awareness of the project in communities of interest, to create an atmosphere of collaborative intent (R. Braidotti, personal communication, August 24, 2017, for more about how collaboration is a theme in Braidotti's work see Blaangaard & van der Tuin, 2014) and to invite potential participants to come forward to engage in dialogue about joining the project. As for methods of recruitment: I invited general practitioners in small communities to hang posters in their offices (see Appendix G for the poster I created for project recruitment); I placed posters in sites women with health concerns frequented (Canadian Cancer Society regional offices; Pharmasave Wellness Centres, etc.); I placed posters in high-traffic sites (primarily gas stations and coffee shops); I was interviewed for articles in community newspapers (e.g., *Alberni Valley News*) (see Appendix H for content); I arranged interviews and community postings on local cable networks; and I responded to word-of-mouth invitations from community groups to discuss the research project.

With my project goal of inquiry in smaller communities, I kept recruitment to Central Vancouver Island, and within one health authority. There were two sizes of communities in this catchment area. I defined a smaller community by access to a *scope of* *services* needed by participants for their well-being, a scope not restricted to biomedical services (for example, a laboratory for blood work). In contrast, I defined a large community as having a greater range of resources and services, including physical sites of healthcare. Nanaimo was the largest community in the recruitment area. I still considered it as part of the project because of the fragmented and limited nature of local services available and the reliance on larger metropolitan areas outside of central Vancouver Island, primarily Victoria, and Vancouver. To underscore this point, it is relatively common for Greater Nanaimo healthcare clients with a life-limiting illness to seek support and/or be prescribed treatment outside their community. I excluded the Greater Victoria area because of the diversity of services available and the presence of the British Columbia Cancer Agency's Vancouver Island Centre. I also excluded remote communities of Vancouver Island (for example, Port Renfrew) and remote islands accessible via Vancouver Island (for example, Hornby Island) because of the pronounced scarcity of services. I recognized that these remote communities had such a different sphere of daily life, from what I am calling smaller communities. Smaller communities are more centrally located, yet still removed from urban centres.

Recruiting in community, facing new questions. I began participant recruitment in Central Vancouver Island, where several representative communities are located. The first communities were Parksville and Qualicum Beach. With these I included the immediate surrounding areas, for example, French Creek and Coombs. I then expanded recruitment to other communities, in order: Port Alberni, Courtenay, Nanaimo, and Duncan. Given the reach of newspaper articles published online, there was interest expressed in the project from potential participants well outside of the defined geographic area (for example, California, England, and Saskatchewan). I did not include these individuals in the project. I did include one participant from Denman Island and one from Gabriola Island as these small islands are a short distance from the original recruitment area of interest and are connected with Central Vancouver Island because of healthcare service boundaries, as well as opportunities for employment and lifestyle. In addition to Central Vancouver Island, one participant from the Highlands area of Southern Vancouver Island also fit project criteria for recruitment, because of the way they accessed services.

In addition to refining which communities would be included, early in the recruitment process, I also needed to redefine my original demarcation of whom I would consider to be a potential primary participant. Right at the start of recruitment, four women with non-typical or ambiguously categorized breast cancers contacted me. Their interest in the project sparked further conversation about who exactly was a woman with ongoing MBC? Diversity in advanced breast cancer became acutely real, in terms of physical manifestations of breast cancer and women's embodied understanding of their illness. Despite their many differences, the women who came forward with ambiguous breast cancers all shared the following: they did not have primary breast cancers, did not have a clear sense of what their current advanced breast cancer status meant for their lives, and did not feel well-served by community resources in their area. However, how did this fit with my project? Based on how my underlying interest was in shifting terrains of living⇔dying today, there became a need for me to sharpen the artificial but pragmatic divide between different advanced breast cancers. I revised my criteria so that I would invite women who had medical evidence of breast cancer metastases, had some form of an active healthcare treatment protocol for cancer, and identified as living with advanced breast cancer for at least two years.

Language use for recruitment. Throughout participant recruitment I worked with a posthuman sensitivity in applying language to describe the life-limiting illness of interest. As expressed in Chapter 2, I am using the phrase ‘metastatic breast cancer’ for this project because it speaks directly to material processes of cancer, and it is embodied in a way that advanced breast cancer is not. The etiology of metastatic speaks to movement, and I am interested in embodied landscapes of suspension known to women, suspension being a particular manifestation of movement⇔non-movement. However, when working with participants, I needed to acknowledge how the word metastatic can be off-putting and/or inaccessible (as medical terminology). I worked with tensions of the descriptor metastatic throughout this project, but it was in participant recruitment where it was most evident.

With descriptive language used in the recruitment strategies, I worked to strike a balance between the project’s formal criteria for participant recruitment and phrasing that would be widely accessible for potential participants. Within the constellation of advanced breast cancer that includes MBC, certain discourses and wordings are not common in popular parlance. I particularly considered how it cannot be assumed that members of the general public know the details of medical terms. Further, in a time where both cancer and breast cancer survivorship has become part of the social sphere, advanced breast cancers are less socially acclaimed or accepted. Advanced breast cancer is one where there are still numerous silences, references to degrees of failure and other social indicators of a cancer that is Other. Specific to recruiting participants, I had focused conversation with committee members on how the language of 'advanced breast cancer,' 'metastatic breast cancer,' 'non-curative breast cancer,' and 'stage 4 breast cancer' might work in community spaces.

As a matter of best fit, I used different language for each of the recruitment methods. For posters, I did not use the static narrative, the highly specific, and the technical term metastatic breast cancer. Instead I used the phrase non-curative breast cancer (advanced or stage 4) in an attempt for greater accessibility and approachability. The use of the phrase intended to invite curiosity and interest with its comparable open-endedness. I did use metastatic breast cancer occasionally in media interviews and in preliminary conversations with potential participants. For the initial telephone conversation with potential participants, I began with more accessible language and then was able to gauge the comfort level and preferences of each person I spoke with (see Appendix I for the ethics approved script). With interviews of all kinds, these were fluid conversation sites where there was room for a clarifying, compassionate discussion.

As with written and spoken language, I critically considered the visual language I used on posters. I used a graphic within the mainstream sphere of breast cancer to signal to readers the general project domain. However, I selected an atypical graphic characterized by a variant of both the breast cancer colour pink and the breast cancer ribbon (see Appendix G for details). The image also emanated a collaborative tone, evoking in part breast cancer grassroots advocacy and supportive cancer care (care with a focus on lifestyle and wellness). As a whole, the graphic could signal to readers that my project was taking a different direction than the norm.

Interview guide. To prepare an interview guide for primary participants, I consulted the literature on feminist qualitative research practice (e.g., Hesse-Biber, & Leavy, 2007; St.

Pierre, 1995). I created a set of potential interview questions and topics meant to facilitate conversation if needed (see Appendix J for details). For the interview guide, I designed two questions that had the specific function of bounding the start and the end of each interview, ones I used in some way with all participants: an *opening question* to create space for deep conversation and a *closing/summation question* as an opportunity for participants to collect their thoughts on living with advanced breast over an extended time period. Both threshold questions acknowledged how the interviews were uncommon thinking spaces outside of the pacing of daily life and each question was meant to deepen research data while threading compassion into the research process.

In conjunction with the interview guide design, I set aside a minimum of two months between primary participant interviews. This break gave participants time to reflect on thoughts brought up by project participation and consider aspects of their life they might not usually. The space between interviews worked much like how I used pauses in the interviews themselves.

The follow-up telephone conversation was more informal, with a verbal script that I used as a pathway for conversation (see Appendix K).

Interviewing with primary participants. Over the course of my research, 14 women joined the project as participants (for an overview, see Table 4.3 and for a written, expanded description of each primary participant, see Appendix L). With each of the women, there were two face-to-face interviews and one follow-up conversation, either by telephone or an in-person meeting (which was their choice). We agreed on a place and time, however consistent with my methodological approach, I followed the lead of the participant as to what worked best for them. The length of time for each interview and conversation varied, as this too was participant guided. The first interviews ranged from 40 minutes to 1 hour, 46 minutes; second interviews ranged from 56 minutes to 1 hour, 42 minutes. Follow-up telephone conversations averaged 25 minutes (ranging from 8 to 50 minutes).

Table 4.3 Project Participants — all information as at the time of the interviews

Participant Pseudonym	Age	Years with MBC	History with Cancer	Current Health Status	Treatment Modalities for MBC	Immediate Family Unit	Work History Since MBC
Kristin	Early 40s	3 years	No prior history.	No signs of health decline. Few cancer-related symptoms.	Surgery and chemotherapy. Has been on one hormone therapy.	Lives with her husband and two young children.	Went from full-time to part-time employment.
Lorraine	Mid 70s	4 years	Primary breast cancer.	No signs of health decline. Fatigue and limited mobility (cancer in hip).	One hormone therapy since diagnosis.	Lives with husband.	Was retired before diagnosis.
Meredith	Early 70s	3 years	Primary breast cancer.	Has been a designated palliative patient since diagnosis. No signs of health decline. Fatigue.	Surgery. Currently on second type of hormone therapy. Also taking cortisone.	Widow who lives alone.	Was retired before diagnosis.
Simone	Late 30s	3 years	No prior history.	No signs of health decline. Lives with fatigue and cognitive symptoms.	Surgeries, one for a brain metastasis, and aggressive chemotherapy. On second hormone-therapy.	Lives with husband and two young children.	Employed full-time, now unable to work (too demanding and detail-oriented).

Participant Pseudonym	**Age**	**Years with MBC**	**History with Cancer**	**Current Health Status**	**Treatment Modalities for MBC**	**Immediate Family Unit**	**Work History Since MBC**
Morven	Late 70s	9 years	Primary breast cancer.	No signs of health decline. Fatigue, reduced mobility, and body aches.	Surgery and radiation. On same hormone therapy since diagnosis.	Widow who lives alone.	Was retired at the time of diagnosis (retirement was related to primary breast cancer).
Mildred	Mid 70s	4 years	Primary Breast Cancer.	No signs of health decline. Fatigue and body aches.	Surgery and experimental high dose of therapeutics. Now on hormone therapy.	Lives with husband.	Was semi-retired at the time of diagnosis, then medical leave, now retired.
Pearl	Late 60s	18 years	Two kinds of primary breast cancer (26 years ago).	No signs of health decline. Lives with few cancer-related symptoms.	Surgeries. Same hormone therapy since 1999.	Lives with husband.	Was retired before diagnosis.
Toni	Early 40s	4 years	No prior history.	No signs of health decline. Fatigue, weakness in arm, and problems with mood.	Surgery and chemotherapy. On hormone therapy. Radiation as needed.	Lives with husband and young child.	Self-employed, since diagnosis has shifted from commercial contracts to smaller projects.
Cynthia	Early 70s	22 years	No prior history.	No signs of health decline. Fatigue, arm weakness and deep body ache.	Has had surgery, radiation, high-dose chemotherapy, and a hormone therapy. Withdrew from regular screening and all therapies 7 years ago.	Lives with husband.	Was retired at the time of diagnosis.

Participant Pseudonym	Age	Years with MBC	History with Cancer	Current Health Status	Treatment Modalities for MBC	Immediate Family Unit	Work History Since MBC
Adrienne	Early 50s	2 years	No prior history.	No signs of health decline. Ongoing fatigue and balance issues.	Surgeries, radiation, and chemotherapy. Now on two clinical trial therapeutics, replacing a hormone therapy. In pre-treatment for targeted brain radiation.	Lives with husband, and teenaged children.	Had continued with full-time employment after diagnosis, now retired (problems with insurance).
Diane	Mid 60s	2 years	Bilateral breast cancer.	No signs of health decline. Reduced energy and upper body muscle weakness.	Aggressive surgeries. On a hormone therapy.	Lives with husband.	Was retired at the time of diagnosis.
Janice	Early 70s	6 years	Early stage cervical cancer.	No signs of health decline. Ongoing fatigue, arm weakness and fluid buildup in lungs.	Chemotherapy, radiation and three different hormone therapies to date. Plural sac drainage as needed.	Lived with new husband.	Was retired at the time of diagnosis.
Darlene	Mid 50s	2 years	No prior history.	No signs of health decline. Most current symptoms related directly to therapies.	Surgeries and radiation. On a hormone therapy.	Lives with husband.	Continues to be employed full-time.
Sofie	Early 70s	3 years	Primary breast cancer.	No signs of health decline. Limited energy and muscle weakness.	On a hormone therapy. Radiation as needed.	Lives with husband.	Was retired at the time of diagnosis.

Typical to these smaller coastal communities, all the primary participants identified as woman and as white. However, my analysis is limited because I am not able to account for racialized differences or for gender expressions other than woman.

In each interview, I sustained a purposeful conversational atmosphere (St. Pierre, 1995), a flexible interview style that supported my goal of embodied and generative story-telling. Shared with oral history approaches (Hesse-Biber & Leavy, 2007; St. Pierre, 1995), I focused on hearing participant life stories covering a particular timespan, rather than strictly adhering to a structured schedule of questions. My focus was on the period of participant's lives from the present back to the time when it became apparent that their cancer was not imminently life-threatening. The nimble interview format allowed me to work collaboratively with participants who were sharing life events that could be challenging to tell, especially given their encounters with mortality.

The format for each of the two interviews and follow-up conversations. The first interview was an introductory discussion. I invited the participants to talk about their lives with MBC so far, the day-to-day of living⇔dying. In all interviews, I used the interview guide opening question to facilitate an organic, story-sharing style. I sought to create a space where mutual trust could be established and where exploratory conversations about encountering serious illness could occur. Most participants started with either a story of diagnosis or a different seismic moment that significantly altered their understanding of what cancer could mean for their lives. With all the primary participants, I used some interview questions from across the interview guide, up to a third in some cases. All participants expressed curiosity about the questions I had prepared and there was interest in partaking in those questions. The first interview worked well to set the stage for nuanced follow-up conversations.

At the end of the first interview, to accommodate any potential health limitations participants might have, I offered them the opportunity to share stories in more than one medium. I asked each participant if she wished to write a brief account of how they had come to think of living with life-limiting illness over time and whom they were becoming. I suggested that the written account be about 1–3 pages single-spaced or equivalent. Two participants engaged in this practice. I had also prepared alternative options for those participants interested in writing an account, but where writing was not a pragmatic option for them. However, no one used this option. Additionally, I invited participants to share diverse resources that influence who they are as individuals with an ongoing life-limiting illness. Examples of resources include brochures, friendships, medical artifacts, and photographs. Five participants shared materials.

The second interview was a space for elaborating on and going into greater depth on topics that participants raised in their first interviews. If participants had chosen to do the writing practice and/or share resources, discussion of assembled material was also part of their second interviews.

Although not planned, the second interviews were more structured than the first interviews. All participants discussed updates on what had been happening since their first interviews. The gap between the first and second interviews varied across participants; however, this gap was at least two months for all participants (as set out in ethics application). In the second interview the women covered the ups and downs they had experienced. By the direction of the participants, most of the second interview was used to discuss questions from the interview guide and/or streams of conversation spinning off from the guide. Significantly, all participants revisited story fragments from the first interview that were particularly important to them. By doing so, they added generative nuance to their accounts.

The brief follow-up conversations with all participants offered a free-form opportunity for discussion. These conversations generated further thoughts and conversations on outcomes of analysis so far. I planned follow-up conversations to be between 15–30 minutes in length. Some far exceeded that amount as some participants had a lot to say.

Processing the interviews as data. I digitally recorded all interviews using Apple devices (an Apple Air laptop, an Apple iPod, or an Apple iPhone). All audio-recordings were password secured. I did not retain digital recordings long-term on these transportable devices. I transferred the audio files to USB sticks and kept them in a secure location and to a secure Internet-based storage account (as outlined in the Informed Consent form, see Appendix C for more details).

To support data transcription for this project, I vetted and retained a professional transcriptionist. The transcriptionist transcribed the digital recordings within one week of each recording. I shared recordings with the project transcriptionist using a secure Internet-based file hosting account. We agreed on a type of transcription style wherein I communicated the need for an evocative, embodied style of interview (Ely, Vinz, Downing, & Anzul, 2005). To better ensure retention of silence, emotions, and other sources of data that might be lost in the translation of oral conversation to written text (St. Pierre, 1995, 1997), when I was first in receipt of a transcription from the transcriptionist, I worked with the original recordings and further fleshed out the transcript (see Appendix M for transcript excerpts). This practice was synergistic with my practice of writing field notes directly after each interview session to preserve embodied data that may not be apparent in written transcriptions and possibly not remembered over time.

I invited participants to email me throughout the interview process. I decided that this would open multiple lines of communication with participants and would find another way to engage a format that worked well with a never-entirely-predictable illness. In my project, this was another ethical action of putting creativity to work in advocacy (Braidotti, 2013). And, it was also an action to keep conversation fluid and responsive in present time, which was not limited by formal temporal structures and research processes (Jackson & Mazzei, 2012).

Cluster interviews. I conducted a set of cluster interviews to gather supplemental information that would bring a greater sense of the complexity in participants' lives. A significant contribution from these clusters was that they acted as a means to realize my posthuman-informed project as a practitioner-generated one, by bringing in additional registers of emotion. Emotions are difficult to incorporate in the various forms of poststructuralist critique but are often part of the embodied terrain of practitioners. It became clear that cluster interview participants' shared materials which were vibrant accounts of emotions as well as the hidden stories seeking to be told. For example, there was a close friend who spoke with admiration of how her friend's wellness was interwoven with the spiritual, including how her long walks were contemplative practices for shedding anxieties and fears. The cluster interviews broadened the scope of what embodied findings could be. These emotional registers were most notable during conversations with the loved ones of the primary participants.

Interview guides. I developed and applied two interview guides modelled after the one used with primary participants. As with those interviews, the purpose of questions was to help facilitate a discussion about living⇔dying. However, for cluster interviews, a professional and a non-professional interview guide were developed (see Appendices N and O). Although both guides were similar, they reflected differences in how professionals and non-professionals would be in relationship with the primary participant and with people in general who had advanced breast cancers.

I did have a provisional plan for interviews, yet how I used interview guide questions was highly responsive to the interview flow and the participant's needs. My application of the interview questions was iterative. When I did use interview questions, there was sensitivity to how close the interviewee was to the primary participant and how much they knew or understood about the disease. For example, the context of whether the participant was a hands-on father, or a Reiki practitioner seen once a month.

The general interview structure was similar for all interviewees. At the start of the scheduled interview time, we discussed confidentiality, and I invited participants to share any material they had that they believed would clarify or enhance what they had to tell. I started the interview itself with an opening question, a threshold to ease into the nuanced conversation. At the end of each interview, I asked a closing question that helped me to trouble and expand the interview material.

Cluster interviewing process. There were three clusters in total. The exact number was a decision made to balance how much data were needed to inform the objectives of the project and how much was fair to ask of existing primary participants. I approached three primary participants and asked them if they would agree to identify people in their lives whom they considered to be knowledgeable about permutations of their life with MBC (see Appendix P for the script guiding that conversation). The goal was to bring people into the research whom they thought had stories to tell that would add layers to what they had already shared. I selected these primary participants because they each represented a different cross-section of women who joined the project in terms of age and lifestyle. I invited primary participants to consider people from diverse areas of their social life, both within their personal sphere and their professional spheres, where they addressed their health needs.

I asked the primary participants who agreed to partake in the cluster interviewing process to provide me with contact information for potential cluster participants. Primary participants spoke with potential cluster interview participants before sharing contact information, and thus I had confidence that there was a willingness of potential participants to hear more about the research project. I then contacted all the potential participants identified and had a preliminary discussion on project involvement (see Appendices Q and R). These discussions included what project participation entailed and issues around privacy. Formal acceptance into the project was by mutual agreement between the cluster participant and myself. The final numbers for cluster interviews were as follows: cluster number one had three participants, cluster number two had four participants, and cluster number three had three participants.

Processing the cluster interviews as data. I had a specific process of working with cluster data to ensure project integrity. I worked with one cluster group of participants in its entirety before moving on to another. I immersed myself in the data generated with each interview in the cluster and thought diffractively across the interviews in the cluster. The next step was that insights from each cluster were thought diffractively across each other. The final step was to use the cluster interview data diffractively across all project data. A process where I read the text of cluster interview data in consideration of other texts, including primary participant interviews.

Key informant interviews. Throughout the project, I identified key informants who could speak to some of the current realities of advanced breast cancer and day-to-day life with advanced breast cancer. I sought key informants to speak about those ‘in-between spaces,’ spaces not obvious to look for, that shape how the women were living⇔dying with MBC. Informants who had embedded knowledges of women living with suspended forms of MBC. Given the specialized nature of knowledge about advanced breast cancer today, I did not restrict key informant selection to the geographic area of the project. Regardless of their location, I conducted all key informant interviews face-to-face. There was also no predetermined number on how many informants I would interview. The main criterion I used to select a key informant was an ongoing identification of informants who could enhance project findings by adding details about MBC or by offering a contrasting perspective. By the end of the project, I had recruited five key informants, of whom I interviewed four (with the fifth there were unresolvable scheduling conflicts).

I contacted informants in consideration of the spectrum of advanced breast cancer support and expertise. I drafted a letter for key informants to invite potential informants. This letter was suitable for either traditional mail delivery or email (see Appendix S). I sent invitations to a breast cancer wellness and women’s health instructor from Central

Vancouver Island, an academic specialized in psychosocial cancer care, a medical specialist from BC Cancer Agency Vancouver known for her innovative application of new medical technologies in breast cancer treatment, a small-town general practitioner known for his creativeness in advocating client-centred care, and an internal medicine bone specialist who knows both diverse presentations of MBC and novel therapeutics.

I conducted most of the key informant interviews near the end of the project, after immersion in primary participant material and engagement in respective community landscapes. I located informants who spoke to the elements brought forward in the stories the women had already shared. Given the interplay of the fast-changing yet inconsistent nature of medical technologies for MBC and those who happened to hold knowledges in community, it was often both unpredictable and surprising as to which practitioners held the most current and/or comprehensive knowledge. For these interviews, I had an interview script (see Appendix T) to help me isolate key topics (Hesse-Biber & Leavy, 2007) however, in conversation with key informants, I worked to delve generatively into topics they believed were most salient given their experiences. I analyzed key informant data as I analyzed the other interview data, diffractively through reading with theory across primary participant data and cluster interview data.

Document collection. I did a comprehensive review of documents to help disclose medicalized understandings of MBC. I was interested in texts which contributed to the project participants' sense of whom they were as people living with suspended life-limiting illness. Document collection was a strategy to realize in more detail my analytic concern for materialities or the entangled swath of forces that are the social landscape (McCoy, 2012).

Contextual factors. With the document collection process, I came to acknowledge two critical contextual factors. Participants had been diagnosed and treated across a wide span of years. Therefore, texts of interest were not confined to a tight or even entirely knowable timespan. A further challenge was that clinical treatment and resources for participants were not limited to Vancouver Island or even the catchment area of British Columbia Cancer Agency, especially in this increasingly complex information age. Moreover, practitioners were also encountering wide-ranging information from diverse and farther afield spaces. However, both factors speak to the day-to-day complexities known to women and thus provided additional contextual information for my inquiry.

Review of documents. For document collection, I reviewed healthcare policies and procedures of the kind that inform practitioners who work with forms of MBC, materials distributed within healthcare spaces that participants could encounter, and materials that participants offered to me that spoke to their understanding of their living⇔dying. Document collection occurred throughout the research project. I did not restrict the collected documents to a specific timespan or a set of dates. A key reason for this was that I decided that no matter the publication year, documents offered by the various interviewees were applicable by the fact that they thought them significant enough to offer. This was slightly different from when I was collecting documents. Then, I gravitated toward those in use for the current care of the women in this study and I attempted to locate material pertinent to the time each of them was diagnosed. When unsuccessful, I sought anecdotal stories from the women and from my colleagues in the field. Although the collection of documents could not be fully planned and was open to change, I systematically collected each document with attention as to whether and how these documents could provide a greater understanding of how women framed and talked about their MBC.

There were documents that I discovered or were referred to me that I decided not to use because they did not inform the participants' experiences in any way. Sometimes my decision came from a place of having listened to the women, and I knew they tended not to value specific resources. For example, I excluded handouts on early-stage breast cancers or breast cancer in general that covered basic topics, such as follow-up after breast cancer treatment. Sometimes my decision to not include material was because the material offered details of living with cancer in one's final months of life. I discarded all the material that was specific to end-stage dying with MBC as it did not apply to the women in the project. I had to be careful when excluding documents, because all documents that might not seem applicable, such as out-dated, highly general and/or had stereotypical understandings of MBC, were still part of the overall social sphere of the women's lives and had to be considered on a one-on-one basis.

To use the material diffractively in my reading of texts, I compiled all material provided by participants into one file box. There were three areas of documents I concentrated on:

> (1) Healthcare policies and procedures. I reviewed regional healthcare policies and procedures informing decisions of healthcare practitioners, decisions that produce effects in the lives of women who were participants in this project. Thus, my review focused on both the British Columbia Cancer Agency and Island Health.
>
> The British Columbia Cancer Agency (2019a) "plans, coordinates and evaluates cancer care with the health authorities across BC to provide equitable and

cost-effective health care for people living with or affected by cancer" (para. 1). There are internal protocols on treating breast cancer that I could not directly access. However, in oncology practice circles the protocols for primary breast cancer constitute a formal approach for practice, whereas metastatic breast cancer protocols are not adhered to as formulaically. Approaches to treating metastatic disease do vary, particularly for disease presentations where there is not a high degree of threat to life and, therefore, do not require radical treatment, such as chemotherapy. For women with more stable presentations of MBC, like those in my project, I kept in mind that it is difficult to quantify the alchemy that informs care and what women are told about their disease. This includes: how with metastatic disease the goal of care from a BC Cancer Agency perspective is adding quality of life not cure; the individual practitioners have different approaches (such as training, life experience); information flow of research findings; and the many different clinical characteristics of the breast cancer being considered in each case (such as grade, location, hormone receptor status). To gain an understanding of how the BC Cancer Agency frames MBC, I reviewed their (2019b) health professionals' resource "Cancer Management Guidelines." These guidelines are available on their public website and are intended to guide practitioners province-wide. Particularly salient is the section on breast cancer and its subsection of metastatic breast cancer.

Island Health is the provincial health authority of interest in my project. The texts of most immediate relevance pertain to their community services and end of life programs. However, specific to participants in my project, the relevance of these texts is more in that they help to explain how women with ongoing, medically stable

MBC typically find themselves with few direct healthcare services available to them unless they are having acute medical events or have been medically designated as palliative. I reviewed, “The Home and Community Care Policy Manual” (British Columbia Ministry of Health, 2019), which comes into play at the times when women are receiving community services. For a sense of the focus of the End of Life program I reviewed the public website. It emphasizes a focus on comfort and quality of life for designated palliative clients. There is also the “BC Palliative Care Benefits Registration” form (British Columbia Ministry of Health, 2017), which provides specific eligibility information (one woman in this project met the criteria).

Regarding both the BC Cancer Agency and Island Health, an overall finding is that there are few texts specific to ongoing forms of MBC, and few of the existing texts fit well with forms of MBC that are not in active health decline.

(2) Materials distributed by healthcare insiders. I explored both materials distributed by healthcare insiders to healthcare patients and materials readily available in healthcare spaces. With such an exploration, I understand and acknowledge that the material available varies highly across sites and practitioners. As well, particular participants actively sought out materials while others did not. However, throughout this dissertation project, I witnessed how paper materials were becoming less common, and digital resources became more frequently used. I can say with confidence that the British Columbia Cancer Agency website is a significant source of information for women diagnosed with MBC.

I reviewed the BC Cancer Agency website because it captures how advanced cancer is being spoken about by the Agency. My review included a database of agency publications. The database was limited in application for my project because most of the MBC information was specific to it as a cellular entity, such as mechanisms of pharmaceuticals. I did use the database concerning particular topics of discussions brought forward by primary participants, such as the quality of mammograms and the application of pharmaceuticals. I also read a glossary of medical terms that was on offer for patients. I did a review of the information kit specific to breast cancer disease and wellness that the Agency offers to women diagnosed with this cancer (British Columbia Cancer Agency, 2015). This kit has a long history with the Agency, and there is a paper packet version. The current online version pivots around a companion guide that details stepwise instructions for wellness. Supplementary material within the kit includes: “The Intelligent Patient Guide to Breast Cancer” (written by medical specialists and now in its sixth edition), “A Nutrition Guide for Women with Breast Cancer” (a co-publication with HealthLinkBC), “My Partner Has Breast Cancer How Can I Help?”, “After Breast Cancer Treatment — What is Next?”, and “Exercises After Breast Cancer Surgery” (published by Canadian Cancer Society).

I also reviewed less common materials that I knew could be found in specific local spaces or found occasionally. For example, until recently a glossary of cancer terms could be found in BC Cancer Agency waiting rooms in both Nanaimo and Victoria. This glossary was the “Cancer Terms: A Guide for People Affected by Cancer” brochure, which was compiled by Pfizer Oncology (2006) for their “we’re advancing oncology to meet cancer head-on” campaign. A less widely available example was the BC Cancer Agency’s “Metastatic Cancer — The Club You Don’t

Want to Join: Words of Wisdom from the Women with Metastatic Cancer Group" (Bell, 2008).

(3) Participants healthcare and wellness materials. I also worked with healthcare and wellness materials that research participants offered to me for the project. This materials review was the one with the fewest number of documents.

All but two women in this project mentioned the breast cancer information kit provided by the BC Cancer Agency. Their comments fell into two groups: those who consumed the material to learn as much as they could and those who dismissed the material either because they deemed it irrelevant to their lives or did not want to expose themselves to prognostic material. One participant was a long-time consumer of information provided by Inspire Health. She used this material to both contest and augment the biomedical information she received from her medical care providers. A structure she used to organize these texts and other holistic texts was "Radical Remission: Surviving Cancer Against All Odds" (Turner, 2014). Two participants spoke of social media resources that they used to gain information about what to expect and to find people like themselves. One relied on the blog: "Booby and the Beast" (2019), after an extended search. Here she finally found information where she was not 'outside' of breast cancer stories. Another relied on a closed Facebook group for people living with breast cancer. She spoke of several allies she had found in that community.

Analytical Methods

Analytical methods describe how a researcher deals with data. In general, my analytical methods used theory as an *aleatory research practice* (McCoy, 2012). Rather than following Deleuze and Parnet's (1996) original rendition of aleatory practice, I am working with how this research practice is applied as a feminist materialist qualitative research method. By aleatory, I mean taking up a research practice of being *on the lookout* for constitutive processes within "the ontological realm" (McCoy, 2012, p. 764) and of staying with the questions that arise around how practices matter (Barad, 2008). I kept in mind that it is large-scale themes or patterns of reality that are often known to us, sometimes acting as common sense. However, it is in the micro-processes of how we are entangled in the world around us that one finds new spaces for analysis.

I break down my analytical methods into processes and practices which reflects more specifically, how I approached the data.

Processes. I developed an analytical approach á la Jackson and Mazzei (2012). I followed their suggestion to focus on analytical processes rather than on prescribed methods. As part of their thinking with theory in qualitative research, they offer various strategies to go beyond interpretation when reading data and processing insights. They offer the process of "plugging one text into another" and reading empirical data through ongoing insights informed by concepts and theories (p. 1). For example, I would use text from an interview transcript and read it alongside material from the BC Cancer Agency's information kit (2015) to make sense of how women who were living⇔dying made healthcare choices while still holding onto their roles as a family and/or community member.

I used four primary analytical processes in my thinking with theory approach: decentering, zigzagging, diffraction, and writing as inquiry. I detail what each of these does below (see Table 4.4 for a brief description of each). These analytical processes are synergistic, and my presentation of them as distinct items in a list is merely a way to talk about them. In practice, I used them simultaneously. They overlap and become less distinguishable as I undertook the analysis. I followed Roets and Braidotti (2011b) as an example of how these analytical processes are used on text. Underlying my use of these analytical processes are specific understandings of data, voice, and truth. Like Jackson and Mazzei (2012), I understand data, as well as data analysis, as way-points for theoretical working and reworking. Data are not end-points unto themselves. I do not privilege voice as constitutive and authoritative of meaning but understand it as "*productive* of meaning" (Mazzei & Jackson, 2009, p. 4). Treating data as interim resting points allows space for voices that surprise an analyst, for example, through their excess and instability (Mazzei & Jackson, 2009) or even their absence. Throughout the research, I sought to embrace voice as offering stories that were not standard(ized) nor easy to tell (St. Pierre, 1997). My understandings of data and voice are congruent with the post qualitative understanding of truth as tentative rather than definitive (Jackson & Mazzei, 2012). Research is not a process of finding truth, but a different process of discovery and disclosure in a world of multiple materialities.

Table 4.4 Processes of Analysis as Part of Analytical Methods.

Processes	Working Definition as Applied in this Project
Decentering	To work with data in a way that supports relational stories.

Zigzagging	To have a multi-layered and non-linear approach to working with concepts.
Diffraction	To read texts through each other, and in so doing to keep open to multiple stories and voices in a single story.
Writing as inquiry	To engage the notion that writing is not neutral and that writing style is part of the analytical process.

Decentering. In my project, I applied decentering to work with data and to develop stories in a generative, relational way. Decentering as a process which involves taking the individual out of a privileged position as the focus of the analysis. Instead, placing the individual within multiple systems of the generation of meaning and knowledge. As a poststructural research commitment, decentering as applied by Jackson and Mazzei (2012) is an attempt to escape some of the 'traps' that characterize humanistic qualitative inquiry, in that the privileged are not assumed to be the norm, and that the margins have stories to tell. Thus, decentering also challenges conventional ways of understanding the subject and how subjects form. I focused on resisting the trap of trying to figure out what participants meant when they said something, which in turn helped to resist the pull to create coherent stories tightly bound by themes and patterns. Decentering assisted me in identifying the usual subjects generated by cancer diagnosis and treatment as well as listening more intently to the women and the relations, including non-human ones, they were engaged with as stories about MBC emerged through the research.

Jackson and Mazzei (2012) work with decentering to offer the practice of interviews as *failed method*. Using this practice, I assessed the limits of the conventional social science interview process and worked with those limits to resist the production of "a coherent narrative that represents truth" (Jackson & Mazzei, 2012, p. viii). I un-framed the interview structure's linearity so that the stories in it could be embodied with the lived concerns shared by participants. In so doing, I resisted having the participant, as subject, be the sole focus of inquiry (Jackson & Mazzei, 2012). In using decentering, I found a sustainable means to operate within the tension of being a practitioner while applying critical theory.

Moreover, inspired by Mol (2002) I understood interviews as opportunities to learn more about the events or practices in day-to-day life that are constitutive of illness. In her inquiry on atherosclerosis, decentered the person *with* atherosclerosis and considered the agentic role of medical practices within healthcare settings, medical equipment, and the spatial layout of the clinic to consider what creates the disease beyond the diagnostic and treatment protocols that focus on the person. In my project, during each interview, I listened for participant descriptions of the material events they live within. By decentering the participant and focusing on the relations the participant was situated in, the materialities that were part of bigger stories of living⇔dying provided data that was not solely about the meaning of MBC and the feelings about being ill. Further, I understood each interview site as an agential space (Barad, 2007). A space whereby the stories emerging were generated by the participant (and myself as the interviewer) navigating (positive and negative) force relations. In this space, the stories told came about not only through the repeated consideration of the topic of inquiry, living⇔dying with MBC, but also the location and other material aspects of the interview itself (Mol, 2002). An example of how location of our interaction mattered was in those interviews conducted in a woman's home or other regular (or routine) site of a woman's daily life. Building on these decentering approaches in data analysis, I used data as an expansive site of contradictions, uncertainties, and entangled sets of relations.

Zigzagging. I take up Jackson and Mazzei's (2012) rendering of Deleuze's zigzag as a non-linear way/path to open working/playing with concepts. Concepts are read across data with the hope of having a multi-layered approach to figuring out what might be going on, one that amplifies registers of complexity. Applying Deleuze in such a way can ignite new lines of thinking, going beyond "easy understanding" (Mazzei & McCoy, 2010, p. 504).

Part of the appeal of the zigzag at work, much like following a hare's path (see epigram above), is that it is not predetermined. There is resistance to how interpretation may intrude upon the story being told, by containing rather than expanding what is revealed. Applying concepts is an act of being open to surprise and following where it may lead. Including, if needed, to jump to the side after meticulously tracking a pathway. At the heart of zigzagging is the desire to avoid, trouble, or disengage foreclosure of knowledge generation.

Diffraction. I use diffraction as Karen Barad does (2003, 2007), where she replaces the idea of reflection with that of diffraction. She argues that reflection involves a surface to surface effect, while diffraction is prismatic, offering many light options to a seemingly singular ray of colourless light. In my project, instead of mirroring themes in the data (which would be reflection), I kept open to multiple stories and voices in a single story by being attentive to the various parts of the women's lives (which would be diffraction). Much like decentering, diffraction is a practice that "moves qualitative analysis away from habitual normative readings of data" (Mazzei, 2016, p. 742).

I generated analytical questions that might shift analysis towards a prism for which I was hoping. With these questions (see Appendix U for examples) and the concepts that were informing my project, I was able to produce new analytical questions to pose for deepening my inquiry. I likened this process to Barad's use of prism where the topic, story, and voice were broken down into multiple and constituent parts, which were then sent through another prism to be broken apart, and so on. Diffraction permitted me to work across a set of insights with the goal of exhausting what the data can say (Jackson & Mazzei, 2012). For example, I would read one woman's story about a particular medication regimen that would structure how she organized her time. Then I used this insight about the structuring of time to see that the women used some medications that made them ill for six weeks, while another insight meant that they had to be home every evening, or in Victoria monthly (the site of BC Cancer Agency on Vancouver Island). Sending these insights into each other eventually provided me with the notion of 'temporal pulses' through which I could then write down in the dissertation these stories that the women were telling me.

Two other diffraction strategies were a central part of my analysis process. First, critical reflection (Jackson & Mazzei, 2012) is where the researcher reviews data through an intensive reading and rereading process. Critical reflection receives much attention in the feminist methodology literature (see Burns & Walker, 2005; Bozalek & Zembylas, 2017). My critical reflection is a type of close reading practice that brings to the fore ontological connections that nurture material⇔discursive insights, ones that conventional research (both in and about biomedicine) often neglects. Second, there is a discursive element within diffraction. It is attuned to registers of intra-action to generate new insights for a further critique of data (Jackson & Mazzei, 2012). In other words, there is already built into diffraction resistance to the easy story. All three diffraction strategies — working prismatically, critical reflection, and resisting an easy story — permit me to work with data from the texts until I exhaust what the data has to say.

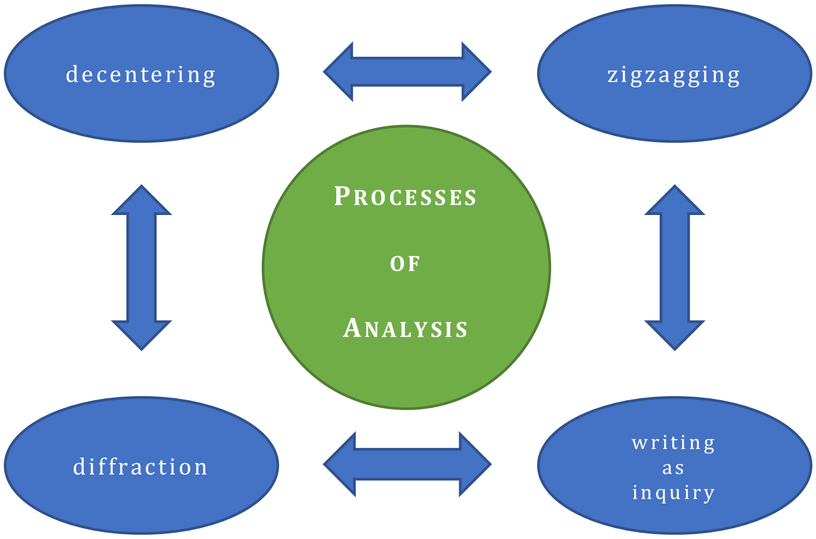
Writing as inquiry. Part of engaging Braidotti's critical posthumanism in inquiry is to also commit to a critically informed writing practice or one that operates in tandem with theory. To put this to work in my project, I again turned to the posthuman work of Jackson and Mazzei (2012), as they provide such guidance for qualitative inquiry. To think with theory is to learn how to write about multifaceted processes happening moment-by-moment and to write them plainly enough so that the reader can understand (Jackson & Mazzei, 2012). I had to find a way to write my relational materialist-informed critique while also satisfying requirements of doctoral degree completion. For example, many of the analytical claims about the data came through the process of dissertation writing, including the writing style and the structuring of sentences. Before beginning to write, I framed the act of writing as an embodied analytic process, hoping to keep the writing tethered in the present and the women's bodily landscapes. I found writing strategies I could use to further ensure writing as another presence in thinking through theory.

The first strategy was from Richardson (1994) and St. Pierre (1995, 1997, 2011), and from their joint publication (Richardson & St. Pierre, 2005), which draws on *creative analytical work* where discourse is understood as deeply material. Their practice offers a writing-without-borders approach that embraces both the lens of science and the lens of the creative arts. It is a critical and generative practice, characterized by humility and tentativeness. I found a structure in their work for my writing practice so I could focus on finding the materialities in the data. I set out to find stories that exist at the threshold of the material and the social, stories which resonate with materialities. A goal inspired partly by Mol (2002).

The second strategy involves *nomadic* writing practice (Braidotti, 2014). As a nomad, I worked against the binary of reader/writer, and I tried to use non-linear language. This strategy helped create space for me as the writer and you as the reader of the work, to ease into a kind of generative ambiguity that is a terrain for 'just big enough stories.' Importantly nomadic writing practice also supports relational material ethics in my project and engages the call for a return of analytical attention to real bodies and real matter. I kept revisiting the question of "how can we account for the fact that women have bodies and pain and live in a real world?" (Hekman, 2010, p. 95). I wrote with the intent to actualize "missing peoples" (Braidotti, 2019, p. 46), breaking "patterns of exclusion" (Braidotti, 2019, p. 45), by discussing subjects who are not often in, or part of, mainstream conversations of living and dying. For this dissertation, I had to temper my writing as a nomad with how a practice-based, academic inquiry is presented and evaluated.

Together these four analytical processes — decentering, zigzagging, diffraction, and writing as inquiry — comprise my analytical approach in this dissertation (see Table 4.1 and Figure 4.2). The heart of my approach is about living in the threshold of analysis as a mediated process of gliding through the data to exhaust it. The threshold is a way of sitting with the data, an opening for thoughts and questions (Jackson & Mazzei, 2012). In this way, analysis is a process of telling something that is not so obvious (also called exceeding the data). In so doing, this analytical process allowed for something new to happen and created a series of new insights that could further 'plug into each other.'

Figure 4.2 Processes of Analysis



Practices. To think with theory in post qualitative research is to think about qualitative data analysis beyond conventional coding. I considered how "there is no recipe for this kind of analysis — thinking with theory — because one has to first read and study carefully and then put it to work in a particular project" (St. Pierre & Jackson, 2014, p. 717).

In putting thinking with theory to work, I tried to stay within the threshold of analysis. There is a need to 'think some more' with the data, paraphrasing a continuing theme in Braidotti's work, and to keep in mind the practical nature of this work, not losing sight of the empirical. I saw the purpose of my analysis as the pathway to draw out the grittiness and the generative flows of Life (see Braidotti, 2010a). Braidotti's work has taught me that both of these are pivotal actions of relational-materialist empirical inquiry. An example of drawing out such grittiness, for Simone, being a mother was a significant factor in her resistance to being called a survivor. This resistance was exemplified by her need to be seen as a mother who was highly aware of her mortality. A mother whom each day worked on being with her children as much as possible in hopes they might remember her, and who kept living an extra day of doing this work, and another, and another.

I did not limit data analysis to a specific timeframe after data collection activities, instead data analysis was ongoing throughout the project. When I received transcriptions of primary participant interviews from the transcriptionist and after each of the other interviews, I dedicated a block of time for working analytically with the new material to engage in the immediacy of it. As my project progressed, I considered new material, zigzagging, decentering, diffractively across other interview data, as I engaged in writing. I situated all data, including interview data, as partial and incomplete (Jackson & Mazzei, 2012). Consistent with a relational materialist approach, analysis was not a process of handling static products that tightly fitted together.

The initial and most salient data handling practice was an affirmative style of coding. Another practice was to organize my insights and notes from my analytical process with the thought of a workable transition of the stories within the data into a recognizable research product. As part of this transition, I managed the intra-active relationship among the elements of my analytical processes most effectively through writing.

Affirmative coding. I came to call my work *affirmative coding.* I chose 'affirmative' because my coding was heavily informed by practical strategies within feminist poststructuralist research, including Braidotti's creative affirmation, and an analytical goal to be non-reductionist in working with data (Jackson & Mazzei, 2012). I also chose affirmative because the coding was emerging through the various decentering, zigzagging, and diffracting, as I was reading and re-reading the transcriptions. For affirmative coding of primary participant interview data, I found that practical sorting of data by a low-tech physical (material) approach was appropriate for the density of data and the various stories being told. Transcripts in the form of paper printouts formed the basis of my hands-on readings and re-readings as I worked with the intra-action of text and theory to disclose the stories that the women were telling.

Through this affirmative coding, I was able to identify *resonances*, in contrast to standard sets, themes, and categories. Resonances are filaments of becoming living⇔dying. These resonances are slippery and leaky, troubling conventional understandings of social science coding (Law, 2004; St. Pierre, 1995). Identifying resonances is not an attempt to gain certainty through finding or uncovering a static truth. Resonances are tentative registers of those 'just big enough stories' of MBC that have been actualized through the research process.

With coding, I was on the lookout (McCoy, 2012) for effects in daily life and anything that would challenge the emerging resonance — even a snippet. I created data chunks, which then became the basis for assembling resonances as material that I could write about. Each data chunk spoke of the materialities at work in women's lives. Working with the paper transcripts, I used a unique colour to denote each data chunk as part of an emerging/potential resonance. As I was crafting resonances, I would read and re-read data. Once resonances reached a level of stability, I formed a colour key. This key was of practical assistance as I worked towards a research outcome in the form of the final dissertation document (Appendix V).

I next applied the intent, but not the mechanics, of affirmative coding practice to data from cluster interviews and key informant interviews. For both cluster interviews and key informant interviews, I reviewed material within twenty-four hours of each interview. I did critical thinking-informed mind-mapping and made diffractive notes by using audio recordings, and field notes were taken at the time of the interview (see Appendix W for an example of such work). Working with cluster interview data and key informant data enriched resonances from primary participant interview data.

Organization of analytical notes and insights. In deciding how I would present resonances in this dissertation, I chose to start by outlining two generative tensions of daily life which threaded throughout the data: *destabilization of the body* and *knowledge mediation.* Both were outcomes of how I undertook data analysis. These generative tensions were a starting place for working towards more specific resonances. They are disclosures of both lived uncertainties characterizing an MBC that continued going on and sustained efforts of women to have a sense of order and/or clarity in the disjointed array that was the overall fabric of their daily lives. They are also a disclosure of forces underlying how women pull together a sense of who they are as individuals with an advanced, but not advancing, cancer. Having this preliminary understanding of the data created space for focused discussion on these factors so that I could move forward in analysis.

These generative tensions led to how I organized the outputs of my affirmative coding practice into the resonances of: *temporal pulses* and *living in bodily transpositions* (see Appendix V for a coding key). In account after account, women disclosed how both registers of temporality and living within an unpredictable, shifting bodily landscape were generative forces in their daily life with suspended MBC. The resonance, *temporal pulses*, speaks to both how time was not static for the women but imbued with tension, and how there was an ebb and flow of an illness that was both present and absent in real-time. The resonance, *bodily transpositions*, speaks to how women mediated living with few set waymarkers, and how the 'hope' they held became an enlivened kind bound with endurance.

Writing as part of analysis. As noted above, writing is part of the process of data analysis within a relational materialist approach. In terms of practical actions, writing as inquiry materialized in several ways. First, in the writing process, I stayed with the mediated tension between the project's need for both accessible empirical language and non-linear language consistent with feminist relational materialism. Finding a still point upon which my work could rest, even if only fleetingly, was a key goal requiring particular attention. Second, I sustained a particular writing style and worked with it as a creative project of many steps, a process of coming to the page and out of abstract thinking. Part of this process was ongoing re-engagement with the treatise that writing, particularly academic writing, "has to challenge and destabilize, intrigue and empower," all the while being "intrinsically political and explicitly ethical" (Braidotti, 2014, p. 166). Third, during the editing process, I engaged with writing as inquiry principles to nurture embodiment and situatedness in the presentation of my findings. I intended my presentation to be a discernable entanglement of the women's stories, my project writing style, and compliance with degree completion guidelines.

Conclusion

For this chapter, I reviewed the methodological elements of my post qualitative informed research project. I discussed methodological principles and ethics framing the research design. For research design, I covered the methodological decision-making and the practical steps that led to project completion, including data collection methods and analytical methods supporting data analysis.

In the next chapter, I turn to a discussion of temporal pulses, one of the two resonances that were an outcome of analysis (findings). My discussion of temporal pulses builds on the generative tensions underlying daily life, as discussed in this chapter and connects with the other resonance of bodily transpositions.

Chapter 5: Temporal Pulses

> Always in a hurry, pre-diagnosis and then our medical system, well, we have to wait for this, wait for that, any questions I ask they say, “We don’t know. You’ll know if you’re here five years from now. You’ll know if you’re here ten years from now.” So, it [having ongoing MBC] taught me tolerance that way.
>
> — Cynthia, project participant

Pulses of time shaped the women’s lives: “cancer is always about time” (Jain, 2007, p. 84). The temporalities imbuing these women’s daily lives were those classically associated with an advanced cancer, as in death being on the horizon (e.g., Stacey, 1997) or death, whether physical or a sense of mortality, is always part of the equation somehow. However, the accounts of women in this project disclosed how time was “structurally unhinged,” without a definitive trajectory given the warp and weft of today’s technologies, especially within medicine (Braidotti, 2013, p. 74). Even for women whose cancer appeared to be dormant, their life timewise tended to be unsettled, unpredictable, and inconstant. Temporally, women’s accounts complicated the framing of MBC as a ‘chronic’ health condition, one that continues without an end. In contrast to *chronos* as a temporal progression where one moment follows another and then another, the women’s lives in this study tended to showed *aion* time at work. Aion time is unbounded and unfettered, serving as a destabilizing force that can upend the present (Braidotti, 2011b, 2019). Aion time pulses and interacts with particular places. For this project, sorting out how women with MBC wove together the temporal aspects of their lives is one strategy to trouble the building of stories as too big or too small.

The women in this study lived within asynchronous temporal landscapes where rapid accelerations and decelerations of time would jostle their experience of linear time into a series of stutters (after Braidotti, 2013). These landscapes were not merely marked by intended outcomes, such as the containment of cancer, but also by the unplanned for circumstances, such as fatigue replacing the more familiar physical decline. Some of the women lived their lives with a pronounced absence of linear time. For other women, linear time was a fleeting occurrence, while others hopped in and out of linear time, depending on with whom they were interacting. Living with forms of MBC as a life-*limiting* not life-*threatening* illness is a life where, for the women, notions of what counts as linear time is shattered and replaced with different understandings and experiences of time. Such reframing of linear time was not specific to cancer, as the reframing took place across the expanse of their daily lives.

In this project, two of the most potent mediators of temporality, temporal pulses, and temporal landscapes, are what I am referring to as strata and place. First, strata are specific periods of time that become emotionally charged layers in women's lives and come to shape their embodied understandings of what it is like to live with MBC. Unlike with acute cases of advanced cancer where time structures women's lives in terms of a steady decline with a somewhat predictable endpoint, for the women with suspended MBC, time organizes life in terms of negotiating the remnants of the diagnosis day-in and day-out for years. For example, Kristin spoke of how, "it's so different from people that have a lower stage, because they get to move on from that [being a cancer patient living with risk]. They don't have to go to the Cancer Clinic every three weeks." In addition to these remnants, there are future layers of time containing even more experiences, such as encounters with the categories for measuring ‘good’ health, which includes being referred to as ‘cancer-free’ or being told their cancer is ‘dormant.’ Given the rapidly changing nature of breast cancer knowledge and treatment, the longer women lived with MBC, the more they were shaped by what they had first learned about MBC, both in general and in their case. In a sense, these strata freeze particular moments that then serve as a grounding point for women as they navigate knowledge of the cancer and their bodies, as well as inform what new information can or cannot be taken in. For example, Mildred was now cautious and skeptical when dealing with the BC Cancer Agency, because of a past event where a new metastasis was classified as a different kind of cancer and, as a result, she was told that if she wanted to continue with a particular drug therapy, she would now have to pay privately. Second, place speaks to how living in the day-to-day smaller community context framed how women lived. Place for the women in the study, tended to be a network of relationships within which each woman had to mediate changing relationships, shifting knowledges, and fluctuating care options. Diagnosed with MBC, these women became aware of the long-standing limitations in accessing care. However in living longer, their lives became mixed with different possibilities for gaining greater access to supportive technologies both closer to home and further afield. In this sense, place broadened through these relationships, thereby making the women not as insulated as women in the past because of how they were situated within their community. For example, Diane relied on an online forum with other women to sort out treatment for her cancer. Darlene also had connections with a medical expert consultant on the American Eastern Seaboard and a leading cancer expert in Ontario and used her up-to-date medical information to choose cutting-edge treatments in the United States. Due to where they live, women worked creatively to have a wide-ranging awareness of what was to be on offer and what could be next.

In this chapter, I organize my discussion around temporal pulses: (1) experiences of time were loaded with emotional tensions and (2) frequencies of MBC were both present and absent at the same time. First, for the women, time was *loaded*. By loaded, I mean that rather than being a static process and a sense of progression, time itself was imbued with affective tensions such as anticipation, anger, guilt, or boredom. These tensions meant that daily life was marked by oscillations and varied sequencings that caused the flow of life to stutter, sometimes creating incursions that would suspend the women's lives rather than grind them to a halt. Second, women embodied this suspension from MBC as a tension of absent but present or present but absent when MBC did not visibly or sensorily mark the body in the now. In this pervasive ambiguity, women frequently located and relocated their dying process, as they lived in a social world permeated with the possibility of their life being ruptured with a new definition of what they would come to understand as 'normal.' The ruptures would pull the women out of the absence of MBC and re-mark their body, making the disease present again, as their earlier understanding of their body faded away. Together, these two resonances of temporal pulses disclose the permeating nature of living with MBC. Specifically, the women's daily life as infused with temporal discord and inconsistencies emanating from diverse sources. These included potentialities of women's bodies, rapidly shifting cancer therapeutics, voids of no technological advancements, accessibility of therapeutics, normative standards of survivorship and healthcare directives.

Loaded Experiences of Time

For the women in this study with MBC, experiences of time were loaded with tension, most often in the form of emotions and energy expenditure patterns. For example, emotions were an omnipresent force influencing bodily endurance. With loaded experiences of time, the idea of *pulse* captures the speed of temporal movement in terms of acceleration, trickling, deceleration, and suspension. Loaded experiences of time were connected with both more classical factors such as treatment scheduling and rapid developments in cancer treatment. Women with MBC in this project lived “the fast rate of progress and change undergone by contemporary biotechnologies and the challenges they throw to the status of the human” (Braidotti, 2013, p. 117), keeping them off-kilter somehow, always mediating change from external biomedical sources.

Three sub-resonances were most salient. First, distorted experiences of time where both timing and speed were significant forces permeating the women’s lives with suspended MBC. With distortion, women felt the jarring effects of temporal disruptions that churned life into something they needed to manage. Second, women lived with the sequencing or regimentation of the flow of daily life. As the months wore on, life might or might not be as heavily structured by healthcare directives or treatments. Nevertheless, plans and actions for ‘living better with MBC’ tended to structure the rhythm of the women’s lives. Third, as part of a palatable suspension, the women lived with undesirable stretches of time, such as wasted time and durations of waiting. Here time holds the women’s bodies while creating something different, where their choices and actions for living are curtailed in some way.

Distortion: Living with Repercussions of Temporal Oscillations

The women in this study lived with temporal distortions from both previous encounters with life-limiting illness and possible futures of the cancer they lived with today. These encounters as part of their story might include a primary breast cancer (if they had had one), a family history of cancer (for several women in this project), or stories within social media (including how a few women said that having breast cancer was quite different, unexpected, than what they had heard of before diagnosis). Quite significant was how all the women spoke in detail of how healthcare providers had described their health status when diagnosed. Some women had first lived with what they had been told would be a life-limiting illness labelled as either palliative or end-stage. For most of the women, the diagnosis was described as some variation of: a serious illness that might allow them to live for many months or even years. Part of how a temporal distortion worked in these women's lives was that the frenetic discordance characterizing the time of diagnosis with an aggressive cancer was not how their lives would necessarily continue. Instead, their lives veered off into a myriad of never-fully-foreseen directions. For instance, after a period characterized by urgently engaging in therapeutics and being close to a palliative designation, Janice's symptoms were now controlled to the point where she had time and health for cruise ship holidays and for marrying a new love interest.

Commonly generating these distortions was the fragmentation and the changing speed of the delivery of information about MBC, particularly by healthcare service providers. A recurring thread in women's accounts, whether they were living with MBC for a couple of years, several years, or well over a decade, was when they were shaken out of linear time. There was the account from Simone, who, after her MBC diagnosis, decided with her family to move from Northern Canada so she could have greater access to treatment. The move did allow her to take full advantage of being under the care of a renowned oncologist, including commuting to Vancouver for a highly specialized surgery. She described her life with ongoing cancer therapies as “a natural kind of storm, then calm, then storm, then calm, then storm, then calm.” Cynthia spoke of how she experienced distorted time as a jolting non-linearity in healthcare encounters: “always in a hurry ... pre-diagnosis and then our medical system, well, we have to wait for this, wait for that.” The women were aware that their lives comprised temporal shifts evoking possibilities, commonly ones they had not anticipated or chosen. These temporal shifts were an aspect of how women knew *through their bodies* that MBC was not static.

Speed mediated the movement of time and often led to some form of distortion. Speed was a factor in women’s ever-emerging sense of who they were in the context of living⇔dying with MBC, including how things were going health-wise. Many women talked about how fast events could unfold. Kristin described how the speed of the initial information mattered, “[i]t was just mind-boggling that, not so much that it happened, but I think how serious it was, how quickly.” Kristin also discussed how speed could take the form of a sudden stop:

> [W]hen I'd finished all of my treatments, the worst happened after that, the absolute worst time of this whole two and a half years was after that. And part of it, I still don't really know. You're completely dropped from the system. I was cancer-free, I'd finished all my treatments, but I was sicker than a dog. I had nausea every day.

One of the things speed does is it takes you for this ride and then suspends you with nothing to hang on to, except a diagnosis or some other static medical status.

With variances of speed, in the form of acceleration and deceleration, there were many accounts of how tests could lead to periods of waiting, followed sharply by the need for urgent action.

> Then we had the surgery. Yeah, it was just a really .... it was a hard 48 hours. I was really angry, really fast. And we kept the kids out of school on the Thursday because I was having surgery on the Friday. Cynthia

> And she [her oncologist] was in Portugal, 12:30 at night in Portugal. And she immediately called me (after new tests results arrived) … she emailed me right after she called me and said, "you need to go to Vancouver right now." Simone

For Simone, temporal oscillations manifested as she did the work of leaving quickly to take advantage of a sophisticated, radical procedure that could only be accessed in the larger city. The speed with which this happened required movement of several disparate parts: in addition to travelling from an island to the mainland, there was also the re-arranging of day-to-day plans, including those involving her small children. In this way, speed generated a kaleidoscope of emotions and life-alterations after the reading of a diagnostic test or a late long-distant phone call.

Interwoven with speed, the specific timing of information healthcare practitioners provided to the women was also important. Rarely was significant news or health updates delivered all at once and in the present time. Women were often in receipt of fragments of information, which were not always enough to be an effective way to connect the pieces within a greater arc of their life-limiting illness. Kristin had first been diagnosed with primary breast cancer, but over several months she received a trickle of updates about her status until she was told she was stage 4, "every phone call got worse and worse. So, I read up on each stage." Each piece of information she received reoriented the way that she took up the illness, her life.

These distortions in time were common when women needed to go outside of routine daily medication or treatments, such as times of screening or short-term treatments. At the time of our interview, Sofie had just returned from screening tests. The incomplete information she had managed to acquire had generated new and different questions for her. She spoke of her concern that cancer might be "going to go to my brain because that's what they (one of the clinicians at the cancer agency) say." Sofie went on:

> [t]hey're (a clinician at the cancer agency) just saying my left cheekbone and I'm thinking, what is that? That's all they say, so they don't really … because they don't know, I guess?

Lorraine discussed how following an initial screening, she was told she had a malignant cancer, dire news with little discussion of treatment or any healing prospects. Four days later, a different clinician told her that it was a breast cancer requiring removal of both breasts. These contrasting stories collided over a short time, a stuttering that dramatically altered her sense of health status, as well as her sense of being a woman.

The embodied effects of timing for the women were also evident in relationships with their families. Most women recounted a highly stressful challenge of having to deliver a significant piece of news more than once. For example, several women spoke of having to share the disappointing news with loved ones that all was not resolved, and further tests were needed. Women also spoke of the challenge of having to revise news they had given to loved ones, despite having checked with clinicians that they had the most correct and final information; a discovery that could come within days or weeks of delivering that news. For example, Adrienne, who had been in ideal health, received a stage 2 cancer diagnosis on a Friday and spent the weekend discussing this with family members. On Monday, however, she was informed there was cancer in the bone and that hers was not a stage 2, but a stage

4 cancer, “and having to deliver that information to my family, I mean, I have no idea how.” When I spoke to Adrienne, the challenging event was months ago, yet her array of facial expressions and pain-softened voice disclosed the embodied residuals of this encounter as entangled with speed and timing. When I spoke to the husband of one of the participants and the parents of another, such effects were prominent in the form of lingering unrest at how events had unfolded.

Temporal distortion for the women implied that routine, manifest as a type of normalcy, could splinter or come apart at any time. In this sense, temporal distortion is a ragged process shaped by variations in speed and how these distortions wended their way through women’s lives.

Sequencing: Regimentation of Daily Life

There were ebbs and flows in the temporal structuring of the lives of women living⇔dying with MBC. To live with ongoing MBC also meant that there was a regimentation of day-to-day life, including restrictions around how time was organized. All the women, at some point, had periods of restrictions where, for example, life pivoted around an ill body and intense illness management. The early days of MBC were often organized around the sequencing of time, primarily around protocols linked to initial treatment and practices in healthcare for advancing disease. Once the regimented protocols ended, when the women experienced suspension with MBC, temporal sequencing became more irregular. So, even though there may still be the occasional healthcare order, there were typically healthcare or treatment *recommendations*. There was more choice over available healthcare and treatment options that could space out over a series of weeks or even worked into the existing daily schedule.

Fraught with what she described as “frustration,” Mildred discussed how time was never entirely your own with MBC. She spoke of the tension between being relatively healthy and still having MBC. For instance, she regularly sparred with those working at the BC Cancer Agency scheduling department:

> Like it’s my life that’s going to be lived or died. [The] administration does not [take into account life outside of being a ‘patient’]. You work under their rules. So many times, I’ll get an appointment, and I have plans already. We’re not even going to be here.

Her life with MBC was a temporal double-edged sword where she found herself with more time to live, but simultaneously with unanticipated demands on her time.

Women disclosed how structuring their lives to one degree, or another was an array of illness-related happenings. Such happenings were in addition to daily needs and demands of time. The illness-related events determining the sequencing of women’s time included: cycles of chemotherapy, timing of medication during the day, and length of recommended recovery from treatment. There was also sorting through feelings about MBC at various times after diagnosis, negotiating bodily energy to determine the length of excursions outside of the home, and scheduling social and general daily-life appointments around commitments to treatment regimes. The specifics of each happening also manifest at different temporal scales. For example, Meredith discussed how she measured her outings by how long she could comfortably wear clothing she considered appropriate for being out in public. Simone spoke of how the illness took on the shape of six-week time bytes: “six weeks to recover from the surgery … six weeks to recover from chemo … six weeks to recover from radiation.” She later noted the lengthening in months in terms of her engagement with her illness: “I go to my oncologist, that’s in Victoria, that was every six months. Now I’m every nine months.”

Unsurprisingly, how actively involved women were with healthcare systems, determined the degree to which sequencing restricted living. For those engaged with clinic-based therapeutics or pre-scheduled routine follow-ups, the community aspect of how far one needed to travel and when appointments were available affected the fluidity of time. Most women found themselves working with schedules that included commuting to larger centers, most commonly Nanaimo, Victoria, and Vancouver. For Diane, who lived on one of the Gulf Islands, time was shaped by the approach she developed for getting into treatment without “wasting” too much time based on the closest city possible. Her approach included making use of nighttime MRIs for formally scheduled cancer care. An example of living with time highly regimented by cancer was Simone and her family, who felt a financial strain as she could no longer work or seek employment. In speaking about chemotherapy, “[t]he six weeks of on, off, on, off. And that just explains life for me.” Likewise, for Darlene, her structured time revolved around a 12-week schematic. The frequent occurrence of time as regimented by days or weeks became formulas for daily life. Women tended to live with highly regimented schedules when partaking in aggressive therapeutics beyond daily at-home medication. As did some of the women engaging in surveillance in the months following diagnosis.

Moving away from MBC discovery, structured time in the form of strict schedules tended to decrease incrementally for most of the women. Women who were mostly removed from the BC Cancer Agency, but who would get checked for a recurrence or a spread of cancer once or twice a year, tended to have the least rigidly structured time. All the women, including the one woman who had stopped all cancer surveillance, had the option of using *Telehealth* or routine consultations with an oncologist via video at a local clinic. The availability of video consultations helped reduce travel time but remained, as with all clinic appointments, fixed allotments of time and therefore, was a temporal incursion. However, structured time was always present in the sense that at any time, a sign of possible cancer activity would bring back uninvited heavily structured time.

Once in the suspended dimension of MBC, therapeutics that could be years-long emerged as a distinctive sequencing pattern. Janice, who had once thought that her diagnosis meant "the end of me," talked about how some therapeutics flipped the script of MBC having set a date for death. In talking about her medication, she said:

> I've got six years out of it, you know, which to other people it sounds like a lot, but I want another six and then another six after that, you know. Increments of six every time.

Part of the complexity of suspended MBC was that drug therapies were known to work a certain amount of time and were applied with the hope they would work long enough for another novel therapeutic to be developed. Women in this project were aware of such sequencing, even if they were not on novel therapeutics. In this way, therapeutics were a mix of temporal impositions and restrictions alongside the possibility of an extended future.

For Pearl and Cynthia, the two women who had lived with a form of MBC the longest (see Appendix U for details), sequenced or structured time took on a stealth-like, normalized quality, as cancer-specific routines were now deeply enfolded with everything else that made up the shape of their days. For example, Pearl's daily pill was now merely a part of dinner and "you don't think about it. You just go and do it." Cynthia, now living mostly off the grid of cancer protocols, infused daily life with subtle tweaks to support her standard of well-being. She primarily drew upon her extensive family history with cancer and her years of being a breast cancer advocate in her community.

The forms of regimented time the women in this study experienced were a new spin on a familiar theme for those women who had had an early-stage cancer. The women spoke of temporal markers that they had once referenced to provide some parameters to living with uncertainties of cancer. Notably, several women, including Sofie, discussed the classic “5-year marker of cancer,” which is the belief that if one lives for five years past diagnosis, one is unlikely to experience a recurrence. The women were cognizant of how time sequenced their lives on many scales. They weighed this somewhat normative marker against potential longevity, as to whether it had any merit given their current terrain.

Almost all of the women had previous knowledge of the effects of cancer or a life-limiting illness that became part of their efforts to structure more of their own time. This previous knowledge could take the form of embodied knowing (some kind of experience of cancer), awareness of the history of cancer among family members, or general knowledge from broader society. The women drew on this knowledge as a resource and many times were able to generate options and workarounds that became part of shaping how they structured the time available to them.

Abeyances: Stretches of Waiting, Wasted Time, and Boredom

Abeyance, a type of temporal pulse, was a distinctive feature of the larger picture of the lives of the women in this study. Living with life-limiting illness for women was to know in an embodied way a mix of temporal intensities, or incursions of time, where life could go exceedingly fast, move along apace, go extraordinarily slow, shuffle to a stop, and even seem to stall. Abeyance, a type of stalling, was different from both distortion and sequencing in that it was not so much about either time flowing at different rates or inflexible pockets of time; instead, it was time that was deferred or drawn out. The women in this study experienced abeyance as both undesirable and paradoxical. For these women, such time typically manifested as periods of waiting, wasted time, or boredom. An implication of abeyance was the weakening of endurance, tending to drain precious stores of energy. Rarely involving surprise and upheaval, abeyance was a tension that troubled their endurance and was part of the unease of a life where time rarely was truly still.

Women with suspended MBC withstood many stretches of time just waiting, ones that were often lengthy. Waiting could be something women found distressingly destabilizing or simply part of the package of living with MBC. Janice spoke of one spell of waiting, where she was already stretched thin, partly by previous bouts of waiting time. In speaking about a screening process for identifying new sites, or the spread of cancer, she said that "this time I had to wait three weeks to get a CT scan and in that time I lost 24 pounds in three weeks from the stress." Janice's account of stress and losing much-needed weight speaks to hidden costs tucked into 'living well' (via screening for new sites) with advanced cancer.

Along with the many accounts of waiting endemic to participating in healthcare services, there was also the waiting involved in getting past a treatment goal. As an artist who often incorporated West Coast themes into her work, Toni had hoped to live in a remote coastal town:

> I would like to live, I wanted to move to Tofino. I've always wanted to go there. But now, that would probably be pretty challenging. So, I'm waiting to see. Well maybe things will get better in the next few years with treatments. I don't know.

For women like Toni, who were on effective therapeutics and who followed research on advancements in cancer therapies, waiting was shaped by what may or may not happen next, particularly as their lives might depend on it.

Not all spaces or encounters of waiting were strictly undesirable. The women, paradoxically, found that sometimes the waiting could be generative, and even restorative. A few women, for example, spoke of the time they spent in chemotherapy treatment rooms. The space itself came with various comforts and sometimes provided a chance to rest outside of regular routine. As a pragmatic person brimming with wry humour, Janice had once been "terrified" of chemotherapy but reported that she came around.

> I enjoy coming in. … [The nurse is] talking to me and stuff and she said, "Do you mind being here for five hours?" I said, "You know something? I look forward to it. Where else am I going to [get to relax] … besides having to pay for spa treatment? Where am I going to get nice warm blankets and banana bread and whatever. And just lie here and sleep?"

Early on in what would be her long life with MBC, Pearl turned the tables on the emotionally undermining effects that waiting for news has on her. She refused "to feel like I'm going to drop dead in two or three days." To the best of her ability, she took on waiting itself, as a dedicated approach: "[y]ou panic. And the next time around, I didn't. You wait and see. Well let's see what they've got in their bag this time, right?" For her, waiting could be about getting the timing right and not focusing on MBC therapies until there came a time when she had to think about new treatment options:

> I mean I will think about it [MBC] again …. Because the doctor said eventually it will become immune to the Tamoxifen. But he said, "Don't worry because we've got lots of other stuff. We'll keep on top of your blood work and all that."

Wasted time, another example of temporal abeyance, differed from waiting. Women discussed wasted time in terms of frustrations, anxieties, bemusement, determination, and other emotions that led to the idea that the time could have been spent differently. In discussing her ongoing interactions with BC Cancer, Mildred said, "[y]ou accept more time. More time on the phone, more time ….. I sometimes physically go there … [when conversations on the phone are not working]." She continued, "[b]ut the way they [BC Cancer Agency] work it, to me, it just wastes time, my time and theirs."

There were other kinds of wasted time in addition to those that had to do with administrative tasks. Specific to the time consumed by fears and anxieties, Sofie described feeling compelled to get over her first year of MBC, "you feel a pain; you think you're going to get cancer somewhere else. But I just got past that because I thought I waste so much time thinking about that instead of, just I don't know." This kind of time wasted intense emotions that could have been directed toward creating comfortable spaces or living what life there was to live. Instead, the illness itself could set one up to waste time by being fearful of what may or may not be next. Wasted time was another thread of embodiment that, over time, became more complex and a factor in women's capacity to engage a long game with cancer.

The third type of abeyance was boredom. In contrast to waiting and wasting time, boredom tended to flatten out life to where emotions could be limited, and time passed very, very slowly. For Meredith, boredom crept into the mix of life after having MBC for a couple of years. For her, this included moving into a different life rhythm than when she was quite unwell and enrolling as a palliative patient in healthcare:

> And it changes. Like, for a while, I was all right with it [living with MBC]. But now it kind of gets a little bit boring because you aren't free to do things you could before. So, there's the element of boredom sometimes.

Her boredom was nestled in a bigger unresolvable temporal question about "how long is it going to go on?" Or, how long is this suspended state of living⇔dying going to hold me here in this life?

The question above is not the usual question of 'how long do I have' when first diagnosed with MBC. Meredith's question is more about how long her life might yet be, this new life of hers, the one that is different from what came before. Living this type of abeyance, sustained by the biomedical information offered in healthcare, embodied the unknown for women in this study. Meredith was one of the women who had been told they were palliative or another life-threatening category that suggested a significantly reduced lifespan. Generating this temporal pulse of abeyance was the 'cul-de-sac' of living with an end-stage diagnosis or prognosis for years. She was suspended in a palliative state that does not seem to end.

For Kristin going from the clinical framings of palliative to cancer-free over a couple of years came with degrees of "indefinitely":

> [b]ut as soon as they found out that I was cancer-free, they said, we really recommend that you do this [a specific therapeutic] indefinitely." It was my choice. So even now, my oncologist, he likes to take it to his review board every year and say, "is that what we should still be doing? Does everybody still think [she] should be doing this indefinitely, this Herceptin?" And they all say, "[y]es it is working. That's what we all recommend."

The cancer-free status assigned to Kristin spurred her to give voice to awareness and embodied anticipation that her cancer, although no longer located by surveillance methods, was not gone but held back. For Kristin, "indefinitely," acts in concert with boredom in the sense that nothing about MBC is moving. It has become static. Boredom is a temporal holding pattern where nothing can truly change.

Frequencies of Presence and Absence at the Same Time

For the women in this study, each day was filled with embodied experiences of MBC as being absent while present, while sometimes being present while absent, often at the same time. I refer to these as frequencies of presence and absence. MBC broke through into their daily lives with varying degrees of presence, while also bolstering a sense of ‘normalcy’ when absent. If MBC as classically documented by biomedicine is a cancer that can be bodily known by degrees of decline, as consistent with a relatively short and one-directional trajectory ending in death (e.g., Sledge, 2016), then the MBC the women in this project experienced, was far from being quite so singular, decisive, or trackable. Similar to the women with MBC in Reed and Corner’s (2015) project, the women in my project did not share a readily discernable MBC presence as one illness pathway. All the women in this project spoke of how their bodies could suddenly make themselves known, reinforcing the idea that MBC has some kind of knowable signature and breaking apart the way that MBC had marked their body up to this point. Even if the overall illness arc was one of decline, it was difficult, if not impossible, for most women at any given moment, to tell whether MBC was present or absent. Instead, day-to-day life was typically an ongoing set of interactions that resulted in an array of sidetracks, backtracks, and standstills. Thus, for both the women and those they interacted with in their daily life, MBC might be ‘visible’ or ‘invisible’ at any given time. If acknowledged at all, there was usually only a glimpse of the disease or a glance of silence. Sometimes either the disease or its silence could be as easily construed as any number of other bodily happenings. If there was consistency in the presence of MBC over time, it was that suspended MBC persisted in the day-to-day as an ephemeral and liminal embodiment.

Regarding the frequencies of the moments of 'absent but present,' three were particularly salient in the women's accounts. First, to live with a suspended MBC was to have a shifting sense of one's mortality and to have ongoing questions about the *placement* of death in one's life. Even when death was not at the foreground of their daily lives, it was never far from reach. An aspect of dying could suddenly be acutely present, such as mortality being within a topic of discussion unrelated to her MBC. All aspects could surface as an unwelcome intrusion in the women's lives. Second, MBC, in all its murkiness, was still a life-limiting illness where, when observed in the present, heightened the possibility for the fragile infrastructure of the women's acquired 'normal' to *rupture*. Women came to know that there were and would be, times when MBC seemed profoundly still, deemed stable by healthcare personnel, and even, daresay, absent. However, they also learned that their bodily landscape was never without or outside of cancer. Third, living with MBC for a long time was to live a tempestuous well-being, a restless simultaneity of wellness and unwellness. Such *discord* shaped the women's approach to the illness. They came to be deeply engaged in translating their illness, back and forth, for themselves, and others. These translations often were linked to their engagement with the healthcare system. Women often deemed their bodies the most astute gauge of their fluctuating health status, whether in-the-moment or long-term.

Placement: Death and Decline *is* Located in Time and Body

To be diagnosed with MBC for women meant that death was suddenly part of their present and immediate future. However, when shifting toward living⇔dying with MBC, where to place death in the trajectory of life, became less clear. A primary participant's father spoke in a quiet voice of how he might see his daughter die, which he had never considered possible before. Afterwards, he paused and then said that he no longer understood for certain whether she was dying or not, and he kept not being able to find answers, at which point he became visibly distraught. Regardless of their general knowledge or their particular history of cancer (including the specific time in which they were diagnosed and what they had been told at diagnosis), all the women in this study knew that since diagnosis they needed to contend with a life-threatening condition. The women now found themselves thinking about the possibility of dying and about how dying changed how they understood themselves as they were living. Several women spoke of not being able to relate to mortality or even a serious health concern before MBC. For example, Darlene had been exceptionally healthy, including being a national-level athlete, and a busy support person for others in the communities she was part of:

> And I was the one who would be by someone's side who would lose a loved one, be there to help them and to hold their hand, pray and all that kind of stuff. Not even thinking for a minute that I would be, you know, even remotely in that kind of void, so to speak.

During diagnosis, there had been a swirl of information with each delivery acting as breaking news. For all the women, death and dying were part of discussions. Within the day-to-day living with suspended MBC, the women mediated expected and unexpected reminders of their mortality. Such cues often clashed with the women's current awareness, which acted as a gauge of their mortality. These cues were periodic reminders of death that then cast a particular tone over their lives.

The experience of living with MBC certainly includes thoughts about when one might die. However, all the women in this study revisited their thoughts as part of their questioning of MBC over many months. The women that I spoke with mediated a lingering presence of death via methods of clarification, in some cases questioning whether physical death was still part of their cancer outcomes. Most women at the start of living with MBC thought death was part of the near future. Then questions about how soon death would come, slowly and unevenly transitioned into how much more life did they have to work with because it seemed as if they were living with MBC and not dying from it. For the older women I spoke with, in thinking about physical death at some later time, they often came to connect it more with ageing, not cancer. All the women, with varying degrees of intensity, experienced a tension that death was part of daily life and of a certain, yet likely distant, future.

With death becoming disconnected from an immediate future, mortality as a topic became a threshold for new uncertainties. While each day was not saturated with death-related concerns, there was no return to a life where thoughts on mortality could more readily be set aside. Physical death for women remained an open question that they revisited, often shifting in shape and varying in urgency. At the time of our interviews, a few of the women experienced ongoing anxiety and other fears around the possibility of their physical death. Mildred was the exception where the unwelcome certainty of dying haunted her present, "[death's] something I think about all day every day. It never leaves your mind." More commonly, dying was part of the rubric of curiosity and uncertainty that came with having a cancer without a clear ending. Suspended MBC was an illness where death was not as present through bodily matter but was more present in the questions generated from its intermittent withdrawals and re-appearances.

Janice is an example of how all the women spoke of locating death and decline as part of their illness arc, and how this changed over time. Well before our first interview, Janice had thought a lot about her persistent fatigue and cancer-related respiratory issues. She had thought about these issues when deciding whether to continue with an out-of-town holiday that was a vibrant part of her married life:

> Like I feel, and I could be wrong, but I feel with this cancer, like today I feel fine, tomorrow I'm probably not going to die. It's not going to happen, not like having a heart attack, right?

And she imagined when things started to go "awry" death would be a "progressive" process. She actively unlinked MBC from the social narrative of MBC being a "death sentence":

> I wouldn't say that, well, I find it a death sentence and on August 7, 2018, I'm going to die. That's my last day on earth or anything. No, I'd say you have to take it a day at a time.

Simone's discussion of mortality was an uncommonly detailed account of moving away from locating death as being an imminent threat. Across both interviews, she spoke of death and dying, including how her intense fear of death had faded:

> But the change, I used to think about death way more than I do now. And I think with this metastatic disease you basically, you start off being so scared and then learning a bit more about it and getting treatment and feeling good when you're getting treatments.
>
> Like it's hard to describe but I feel more comfortable being sick now than I did at the beginning because I was scared that I was just going to kind of drop off immediately. But now I know it is more gradual … it's a lot more painful than that.

She also spoke of how “now I understand that palliative is just kind of treating for pain and treating whatever. It doesn’t mean you’re actually [dying].” Furthermore, Simone came to use the language of “dips” to speak of her health, including about the identification of her brain tumour. Framing such a weighty event as a “dip” spoke of death, not as part of the present, “and I know there’s lots of other cancer that you die from. But mine, you don’t hopefully. That’s it.” She added, “there’s a possibility — I’m not going to say a good possibility — that I will die from this but I’m hoping it’s, you know, many years from now.”

For most of the women, palliative or other end-of-life categorizations had not been explicitly part of their own MBC origin story. Thus, for some of the women, ambiguity around death had been introduced from the start, before they would bodily know it. Lorraine spoke of her first encounter with her oncologist and how he applied his practice history of working with breast cancer in Ontario, including one patient who had lived twenty years, “he [the oncologist] didn’t tell me to go home and get my affairs in order. He said I can’t be cured, but it can be managed. So, look ahead.” Regarding prognosis, the same oncologist told Lorraine, “if you take 1000 women, in about two years, half of them will be gone. The others will carry on to varying degrees.” Many women encountered a particular register of ambiguity when they found themselves in the care of healthcare practitioners who seemed situated somewhere between the long-standing social framing of MBC as lethal, and the more recent idea of MBC as a life-limiting illness that can be managed.

While living with suspended MBC, the women came to know a variety of pseudo-prognoses that amplified uncertainty and, at the same time, opened space for questions around possibilities for more Life. For example, over a matter of a few days, Adrienne went from being told by her surgeon that the cancer was in her liver so, “he doesn’t know how long I have" to then having her oncologist say "no, we have quite a bit more time here and I don't want you to think that this is, you know, we're looking at a year or whatever it is." The mixed messages Adrienne received over the years was a common reality for the women and were parallel to the mixed messages from their bodily landscapes. In general, a definitive prognosis or forecast was not part of women's accounts of MBC, whether at diagnosis or a later time.

All but one of the women engaged in therapeutics and screening modalities that tended to give mortality a more solid presence in daily life. The women were acutely aware of how the medications they took were more than just hard-to-translate scientific names and aided their well-being. Women knew most of all that they were *control* measures having a role in keeping cancer contained, perhaps forestalling decline. Sofie spoke of, "never having taken any medication of any kind until all of sudden now you have no choice. You have to take all that stuff to stay alive." The sudden appearance of pills in her life, as part of her regular routine, became a daily reminder of a process of living⇔dying deep within her body, a fleeting glimpse of something not necessarily visible. Given how the women were also aware that specific therapeutics only worked for so long to thwart persistent disease processes, these treatment modalities also evoked for them that any location of death was transitory at best.

Just as therapeutics could bring living⇔dying into the present time, advanced care planning could too. When I first met with Meredith, she was finalizing care plans, making her way through a complex array of unwelcome questions. For example, questions about the "disposal of bodies" and the steps needed to be taken to ensure her wish to "die at home" would happen. All these preparations contributed to her bodily paradox: "I'm not anywhere near there [dying]" but still she needed to address these issues. She grappled with details of her future death, while trying to stay within her good health today.

Ruptures: Daily Life as Permeated with Reminders of Illness

The bodily landscape of suspended MBC comprises lengthy periods of time where a sense of well-being could take hold and grow. However, within these lulls, there was an underlying fragility that could shatter the promise of permanence at any moment. Many of the women spoke of how "reminders" and "triggers" populated any given day and that any one of them could easily pull illness, cancer, decline, and other undesirable permutations into the present. For example, Kristin spoke of an appointment with a cancer clinic nurse who remembered her from a time before:

> She said, "I was just reading up on your file. You are doing really well." And I sat there and was thinking, oh yeah, of course I am. But to see someone's reaction like that, you're reminded of, I'm not supposed to be in this state.

Living with suspended MBC meant that their cancer was always about temporal movement, to one degree or another. For these women, part of the less-obvious workload of living with MBC was smoothing out such ruptures that never completely went off the radar.

All the women in this project had an abrupt experience of moving from 'fully healthy' to a 'stage 4 cancer,' and this added gravity to how fragile the present could be. Many of the women I spoke with had been remarkably healthy before the diagnosis of MBC, but also quite driven and capable. Like Kristin, Simone, Adrienne, and Darlene, Sofie spoke of being "very healthy" for most of her life and the time-to-time encounters where her cancer was brought to mind troubled the veneer that she was healthy again. Sofie had had breast cancer once before, which involved surgery without any long-term treatment for the maintenance of health. She had been close to her fifth anniversary of being free of breast cancer (the five-year marker of 'health') when diagnosed with MBC. During our first interview, she expressed frustration and sadness about this turn of events. While MBC could seem like those other relatively uneventful encounters with cancer, she found that as the months wore on, it was increasingly difficult to avoid encounters that shook any stability she was able to hold.

Reminders of living⇔dying via ruptures came in diverse forms, which could happen at any time. Kristin talked about "triggers" that would shatter her sense of stability:

> But now, as time goes on, obviously those times get longer and longer in between when I think of it. And there's various things. There's always a trigger or something. I watch something on TV or see, you know, look at one of my artifacts, or I still struggle with energy. … So, I can go along and have like a fantastic couple of days and then something will happen that kind of brings me back to reality that I still live with this.

Such reminders could occur almost anywhere, which meant the women in the study could not necessarily anticipate or prepare for them beforehand. Simone spoke of the routine use of a disability ID:

> Going on the ferry, I give them my free ferry pass. Last time the guy was like, questioning it, like I was lying to him or I'd stolen it from somebody else, like my parents or something. That kind of stuff is kind of a reminder.

A rupture that came with some temporal regularity for the women was having to undergo the medical tests they lived with as part of the treatment regimen. Screening tended to be a time of turbulence where the check on MBC contradicted the lives the women had cultivated. When contrasting a friend's experience with MBC, Kristin spoke about how the visits themselves were punctuated with even more reminders of how any semblance of stability could come crashing down:

> Her doctor is very different with her. Mine never, still never gives me hope. He'll say at my appointment, "You're doing really well, you're cancer-free, everything looks good" but, before I walk out the door, he always says, "It could come back at any time in any place." And I'm always left with that. And I understand that they need to do that, but it's pretty horrible.

Such meetings would temporally throw Kristin off her daily efforts to live a life larger than MBC. Janice explicitly discussed this contradiction in terms of feeling good only to be told that there was something wrong:

> When you're feeling good, and you think, hey, I've felt really good these couple of weeks, three weeks. And then you go in, and you get tested and they say, "There's something the matter with her. We've found new lesions here and there, yadda, yadda." And you think, you know, why am I feeling so good then?

Simone spoke of how regularly scheduled screenings always came with undesirable consequences, no matter what the results were:

> I get a blip every three months when I get my CT scan. A lot of them have been clear, but some of them have not been clear. So, I don't even realize what's going on. But all of a sudden, my anxiety starts to rise, and I start becoming a little bit of a bitch. And really kind of short-tempered with my kids … [w]hereas I'm normally quite patient with them.

The possibility that medical surveillance could upend the stability of the present was multifaceted. With routine cancer screening, Cynthia had come to feel anxiety because she discovered that the test results might lead to undesirable news, but also to new levels of uncertainty. For example, tests could provide inconclusive evidence that cancer was active:

> Cynthia: My tumour markers went down a little bit. Not a lot, but they went down a little bit. And he said, "That can be good news." He said, "that can be good news. What's wrong?" And I said, "If they go down, they can go up."
> Interviewer: They can move.
> Cynthia: They moved, right?
> Interviewer: They moved.
> Cynthia: Yeah. It didn't matter which direction they went. They moved. They're alive.

Tumour marker findings were not exempt from human error. During her lengthy time living⇔dying with cancer, Cynthia experienced a reading error where her specialist ended up redoing the tests: "he came back to the original number, and he said, 'Humans are humans. Humans are reading this.'" Cynthia came to evaluate medical information critically so she could have greater control over how such news affected her.

Another part of the multifaceted nature of medical surveillance was that for some stability the women could leverage their options, in some instances and through some difficult choices. For instance, Morven reconfigured the conventional format of medical testing through a staying-within-her-own-community collaboration of her trusted general practitioner and *Telehealth* appointments with the BC Cancer Agency. Cynthia went further when she eventually eliminated the "tailspin" she found herself always in by opting out of screening altogether.

The women in the study spoke about the spectre of 'cancer recurrence' with its various temporal associations and the idea of what a 'recurrence' would mean for someone living⇔dying with MBC. Cynthia described being on "the swing" of breast cancer for 23 years. Her fear of recurrence remained, although it had quietened and had shifted form:

> I'm under no illusions that it's in the past. It's probably in the past, but I know the disease. I know too many women who have made it into the 20-year past and have had the reoccurrence. So, I'm not cocky enough to say, "Yoo-hoo. Yes, I can forget about it."

The women in this study deployed the language of recurrence in slightly different ways, but it tended to be a way of putting to work an already available phrase so they could speak to the potential of MBC returning to its more deadly form.

Discussing ruptures in the form of reminding the women they had cancer, disclosed how bodily signs of illness were far from the only way MBC could be present. Reminders were not a cue to be mindful that cancer was present. Instead, each reminder re-set the question anew about what living⇔dying with MBC meant. An encounter where emotional facets for women could be reopened, reconsidered, and reassessed; an attribute shared with the resonance of locating death or decline. However, with reminders, they were more regular, more diffusive in their effects, and they covered a fuller spectrum of life.

Discord: Living the Day-to-Day of Paradoxical Well-Being

Part of what could not have been known beforehand, and for most of the women in sharp contrast to their initial expectations at the time of their diagnosis, the longer they lived with MBC, the more day-to-day life was permeated with paradoxes and contradictions of 'well-being.' Well-being became imbued with a temporal discord where competing resonances of MBC as life-limiting illness and health statuses co-existed in the present moment. Women lived with disease permutations that they had known bodily so far and with projections of what MBC might be or become in the future. A way the women negotiated this dissonance was through figuring out how MBC tended to be an indistinct bodily force, often subtle or elusive in the moment. Sofie first knew MBC as a "shortness of breath" and "soreness" in her chest, while she felt well otherwise. She was "horrified" when during a subsequent medical inquiry, it was discovered that not only did she have an illness, but that it was a life-threatening one. She talked about an intense emotional reaction to the medical facts laid out before her, as well as to the lack of fit with what she knew through her body. Like with the other women in this project, this kind of early encounter was one that, in hindsight, was a prelude of life to come, one of negotiating the tension between wellness and unwellness.

Indeed, several women spoke directly of how well-being, as a mode of liminal embodiment, was a factor in their ongoing understanding of MBC as an aspect of who they were today. Janice spoke of how, following radiation, "I've never had any problem with [back pain] again. You know, I mean. I still have cancer in my spine, but I don't have any pain." For Sofie, "I don't feel anything there [at the cancer site]. So, it's held down or whatever with the chemo that I'm on." Sofie struggled with finding language to speak of what chemotherapy was doing with her cancer. In discussing MBC as "held down," she disclosed her cancer as both present and absent. Such discord was a kind of "normalcy" for Kristin. After many months of negotiating the effects of what living with MBC meant for her, Kristin had settled into a workable day-to-day rhythm that had known instabilities within a relatively stable existence: "I take medication every day, and I have tons of scars. And I don't look normal, but I do feel kind of normal." The scars Kristin spoke of were physical, on the body, yet there were also clear signs that there was no return to whom she was before being diagnosed with MBC. For women who previously had either a primary breast cancer or a different cancer type, an added tension was how their current life-limiting illness included embodied resonances from those prior cancers.

The women in the project noted that within the general terrain of uncertainties, the body could act as a constant that anchored MBC as part of the present. Most notable were the physical signs that, for a time, there had been active cancer and treatments. Bodily constants for the women in the study included: an enlarged arm from lymphedema (Catherine and Darlene), chronic numbness in various body parts (Catherine and Janice), mobility issues from breast cancer in the bone (Morven), chest scarring and any other remainder of breast removal (Morven, Darlene, Kristin, Cynthia, and Diane), and reduced ability to taste (Janice). Much like Darlene, Sofie said, “I mean, you’re reminded every day when you get dressed that you had breast cancer.” It is not only the visual reminders it is also the actual texture of the body that marks the status of MBC. Diane’s 8-year-old grandson commented on her “groupy hands,” and he asked her about the leathery feel when he held them. Diane said, “[y]eah. I’m on a new drug that makes my hands this way. He said, ‘[w]ell you could climb a mountain.’”

For the women in this study, there was also tension around how, in their daily lives, they experienced people commenting about their appearance or general health, often in marked contrast to their sense of their health. Kristin spoke of what she called “invisible scars”:

> I’m sure I wrote that in there — about invisible scars, which I find is another big thing. Nobody has any idea [what to say] as opposed to say[ing something to] someone who is wearing a prosthetic leg. People can see and know that something’s happened. Whereas for me, no one would ever know. So sometimes that’s good, and sometimes it’s bad. It is what it is, but it’s interesting to deal with.

Darlene spoke of a chance encounter with an old friend:

> She came up to me on the airplane, and she goes, “I cannot believe how healthy you look on the outside and what you’ve gone through on the inside.” She said, “it just blows my mind.” … and she was just blown away, as was the case with the most of the people that I came in contact with on a daily basis. I mean, it’s a different story when I go to see my doctor because you’ve got your clothes off and they’re examining you, and they see you for what you really are.

Indeed, such discord could stem from the concentrated efforts that a few of the women took to manage their physical appearance. For instance, Darlene is a highly driven individual with a public career who has invested a great deal of time into presenting herself as healthy. She was also one of the few women to discuss a wish to sustain a normative appearance of “womanhood.” Darlene wore a specialized therapeutic sleeve that both medically contained her lymphedema and allowed her to wear ordinary clothing more readily. She ensured a plastic surgeon was always part of her care team and wore wigs as needed. Such actions disclosed that a generator of paradoxical well-being was both the workload of living⇔dying with MBC and the work of social belonging.

The women in the study also spoke of how they lived with the absence of life-limiting illness. Pearl talked about her life as defined more by ageing than by illness. For Pearl, the absence of MBC was confounding because she had a family history of cancer, she lived with lung metastases, and she had been taking the same therapeutic for years. Cynthia said her cancer was:

> mute a lot of the time now … I never had any side effects, you know. I did feel very well, because I never felt, like, for a long time, you know, for a long time I didn't feel sick.

Cynthia's comments were like those of Simone, who said, "I thought I was going to be dying. I thought I would be sicker. I've never been sick from cancer, not even once." However, for Simone, like many in this project, she knew the side effects of therapeutics better than symptoms of MBC disease itself.

For the women in the project who wanted to find a reason for having developed MBC, not being able to find one, was quite an unsettling absence. Specifically, there was discord between their past and their present. Adrienne tried to make sense of getting MBC.

> I mean, I thought, why did I get this? It's supposed to be my sister. She was the one that smoked and had distress and all these things. And I was really shocked by that because I've always lived a really …. I mean I've always made a point of really eating well, taking care of myself, getting lots of exercise.

Adrienne was dedicated to and diligent in finding a reason, including genetic counselling that had found nothing of value for her. Her resulting frustration was entangled with normative discourses of cancer prevention as connected with avoiding unhealthy lifestyle factors and of cancer itself, cast as more knowable to consumers, because of historically recent genetic technologies.

Among the women in the project, there was a subtle yet pervasive feeling of simply knowing they had cancer and not thinking about it. Janice spoke of how she no longer "dwelled" on the fact she had MBC, but:

> the fact that you know that you have cancer, stage 4, it's something that's constantly, well not constantly on my mind, but you go to bed at night and its sort of the last thing you think of. [It] is [like] I wonder how tomorrow will be. And it's the first thing you think of when you wake up [it] is [that] I still have this disease.

Such knowing was an element of well-being that all women lived with to one degree or another. Something that was particularly vibrant during times of health assessments, whether by themselves or by others.

Navigating paradoxical well-being as an indicator of the status of MBC was a challenge for the women in this study. It was difficult for them to make and to commit to life decisions, particularly those beyond that of MBC. Many months after her palliative diagnosis, Lorraine cautiously decided to drive again. At the time of our first interview, she was sorting out whether she would continue with the Strata council for her condominium complex. She had told a friend that,

> "[w]ell I don't mind doing it, but probably I'll have to give it up." Well, here I am a year later still doing it and wondering whether I should continue to do it or not. And some days I think this is it. I'm going downhill.

Although she felt well, it was not a space to rest, and she did revisit occasionally how much further she could go on with commitments to others without the possibility of letting them or herself down. All the women in the study discussed the difficulties of planning for the future while acknowledging the waxing and waning of bodily symptoms associated with MBC as a suspended life-limiting illness.

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Conclusion

In this chapter, I discussed temporal pulses resonating throughout the women's lives. Temporal pulses for those with suspended MBC are instances where time has become structurally unmoored and thus unpredictable. These pulses are not mutually exclusive. Instead, they are time-related ways of what it is to be living⇔dying with suspended MBC. Conversations I had with the women in this project disclose how temporal pulses were integral to the story of how they became living⇔dying subjects.

There were two sub-resonances of temporal pulses. First, time was loaded with tensions such that a distinctive part of living with a prolonged life-limiting illness today was an embodied sense of fluctuating time. Tensions included living with the effects of temporal disruptions, mediating the way their lives could become heavily regimented, and struggling through time as drawn out or deferred. These tensions of distortion, sequencing, and abeyances provide a sense of how time was never static for the women. Second, temporally embodying MBC meant living with varying frequencies of presence and absence, often at the same time. Such frequencies included: returning to questions about one's mortality over the months, living with the persistent turbulence that was the potential for ruptures to terrains of 'normal' or 'known,' and discord of well-being. These frequencies of presence and absence in the form of placement, ruptures, and discord, disclose MBC as a fleeting but constant signature in women's day-to-day lives.

In the next chapter, I discuss what I am calling bodily transpositions as another type of resonance, which brings different insights into what I have shared about the lives of the women in this study so far. The insights I discuss speak to how the women embodied multiple positions at once, a non-linear trajectory where they navigated life with few set waymarkers and they had a kind of endurance where they kept watch on possibilities, and created their own brand of hope, cultivating *horizons of hope* (Braidotti, 2013, p. 122).

Chapter 6: Living in Bodily Transpositions

> In their experience, this is what happens. And we know this is anecdotal and it's not studies. But I'm sorry, when you're metastatic you go with anecdotal.
>
> — Diane, project participant

Transpositions are complex boundary crossings that do not follow linear borders of circumscribed conditions (Braidotti, 2006). Bodily transpositions were at work in the women's lives with suspended MBC. For these women, there was no fixed site in any imagined trajectory in which to be located, nor was there a particular site to move to. Life-limiting illness was not so much about moving from one set of circumstances to another as part of a clean-edged transition. Rather, life-limiting illness was more about straddling multiple embodied positions at the same time. For example, the women did not live within the designated parameters of cancer as either clinically dormant or palliative. In the day-to-day, there were few indicators of what had just happened or what might happen next. Cynthia epitomized this view by speaking in terms of "everything" being "grey."

Living in bodily transpositions speaks to how the women embodied MBC as "incurable, but treatable" (Maher, Velikova, & Betteley, 2015, p. 322), wherein the primary status of MBC was no longer that of an imminent death sentence (Lewis et al., 2015). To live with MBC, suspended across temporal pulses (see Chapter 5), meant that the everyday was enfolded in a tapestry of uncertainty where they lived with anticipated concerns about having a life-limiting illness while facing questions about what might their stage 4 cancer mean for them. The women I spoke with lived with tensions of unusable subject positions offered by clinics, doctors, and treatment that did not resonate with their bodily states, whether existing, emergent, or not yet named. For example, Simone corrects anyone who tells her that she is “cancer-free” or an equivalent, instead suggesting “metastatic cancer” or “stage-4” because that is what fits for her. For the women in this project, even being a person with cancer was not constant. They spoke of stretches with no clear symptoms and of specialists speaking as if they had no medical signs of either cancer or any movement of cancer. The women were enfleshed markers of the in-between space that *is* living⇔dying.

In this project, the women crossed various boundaries that shaped how they lived in the day-to-day with MBC. First, to live with bodily transpositions meant, in part, negotiating choice across a range of issues. For example, the women navigated their choices about MBC within a highly restricted field of options. They faced situations where they thought they were preparing for a particular treatment or trajectory only to have the options available to them shift dramatically or even vanish. The women also had to make choices about MBC that pushed them outside of their usual routine and had to assess on an ongoing basis whether each option could be workable for the life they wanted to live. These kinds of choices comprise what could be considered a practice for *self-styling one’s own death* (Braidotti, 2011b, p. 342). Thus, for these women living with MBC, facing choices and making decisions were part of “complex and continuous negotiations with dominant norms and values” (Braidotti, 2008, p. 2) while living with a life-limiting illness that was often in flux. Their lives troubled “hegemonic regimes of medicalised death” (Herges, 2019, p. 88), such as dying with MBC as palliative. Their choices also fit with a feminist understanding of “relational posthuman subject formation beyond death” (Herges, 2019, p. 88). As the women made choices, they moved away from whom they were said to be at diagnosis (medicalized subject) toward whom they had become living⇔dying with MBC. This new subject was both relational and material and arose from self-styling one's own death.

Second, in this project, the women living⇔dying with MBC spoke about disentangling themselves from the identities or labels that had been applied to them by healthcare professionals, family, and friends. For example, the question, "are you a cancer survivor or are you palliative?" existed and was asked in many different forms. In response, as part of self-styling their own deaths, the women worked with the wisdom of their bodies to bring forth identities and labels that defied or refused the existing social parameters. The women engaged in acts of micro-resistance by using their bodies as compasses, including bearings for their mortality. Overall, it was common that in crossing boundaries and self-styling one's own death, the women engaged in the process of learning to both live and die in ways other than what had been offered to them with the diagnosis of MBC (see Braidotti, 2006, Chapter 5 and 2013, Chapter 3). In effect, while living in the margins of a misunderstood illness, the women crafted their own pathway into generative living. Finding their way in this manner, was a welcome shift for them.

In this chapter, I organize my discussion of living in bodily transpositions around two resonances: (1) the act of navigating life in a living⇔dying landscape with few set waymarkers and (2) the act of enduring as a way to use hope to chart possibilities. First, for the women in this project, daily life was often one of creating pathways through persistent uncertainty. Women negotiated their sense of belonging within various social categories, deciphered body signals relative to possible shifts in health status and untangled the confining tethers of ill-fitting health categories. Second, throughout the women's discussions of their daily lives, a persistent endurance was evident, one that was characterized by staying with the horizons associated with hope and possibilities. They continually mediated the shifting landscape of what they might strive for via small *practices of hope* (Braidotti, 2011b) and by embodying pathways for living through an orientation to therapeutics.

Navigating without Set Waymarkers

The women that I had conversations with described suspended MBC as a landscape with only a few set waymarkers to navigate daily life by and even fewer that resonated with their own embodied knowledge. Simone spoke of wanting a "navigator," because she often found herself in situations where she asked herself, "who do I go to? Who do I talk to?" It was common that the MBC known to the women troubled established parameters of illness. Also, they knew that their daily lives were off the map of well-established health trajectories. An outcome was that many of the "mystifying representations imposed upon people" (Foucault, 1982, p. 781) fit poorly with their lived reality. For example, it was common for the women to reject prefabricated wellness labels such as 'survivor' and 'cancer-free' because part of their daily routine was still mediating health concerns. In our conversations, the women disclosed nuances of this found landscape of uncertainties and ways they cultivated pathways for living.

There were three primary sub-resonances of this act of navigating without set waymarkers. First, it was common that the women encountered conflicting forces of belonging. Their lives tended to be shaped by ill-fitting social categories that jostled them and troubled their landing in stable spaces of belonging. Part of their daily lives was cultivating plots of fit, which brought with them greater certainty. Second, all the women in this project lived with bodily uncertainty, that was pervasive, consisting of nebulous body signals and of the questions that they ignited. Life consisted of a trial-and-error process full of sorting out whether bodily changes were illness-related health fluctuations, signs of an ageing body, some combination thereof, or something else entirely. Third, the women often felt confined by the structural and institutional practices and processes over which they had no say, let alone control. This situation illustrates how women's lives were never totally free of illness. One task the women spoke about was the seemingly never-ending effort to untangle health labels and categories that acted as tethers to an illness that they did not see themselves as having. I turn to each of these in order.

Sense of Belonging: Negotiating Social Categories

The women spoke about how their sense of belonging — to home, to family, to community, to themselves, to the illness, to their bodies — shifted as they were living⇔dying with MBC. They spoke of how belonging was often turbulent or awkward. I refer to their discussions as stutterings, short-circuits, and points of solid contact of belonging. Each of these was an encounter with social categories of life-limiting illness from which the women were trying to distance themselves, for example, "cancer thriver." Without a normative breast cancer, cancer, or life-limiting illness, almost all the categories the women encountered tended to be ill-fitting. The women also spoke of how limiting the language and phrases available to them were in trying to speak of living⇔dying with MBC. It was common for the women to experience belonging as an embodied process of being not quite this or that.

In the women's daily lives, there were many encounters of having no words to speak of what they knew about themselves or the illness, as well as encounters where the few words that they used did not fit well. Simone spoke of such a struggle. Grappling for words reflects a crumbling sense of belonging and positions the women in-between ideas about where they fit concerning their bodies and the illness. When I asked her how she would describe her cancer, she replied,

> I just say it never goes away basically. But I treat it. And sometimes, I compare it to diabetes. It is worse than diabetes. But it's that same kind of idea where you're giving yourself insulin and manipulating your body all the time.

For the women, inhabiting in-between spaces of belonging meant that, belonging tended to generate yet another layer of illness workload for them. For example, it was common that not having a tightly defined health identity could be a barrier to their efforts to locate resources specific to their needs. Jarring outcomes of turbulent belonging for the women included not being able to stay long enough in one site of belonging to have discernable stability or being locked into an undesirable socially available category. In response, they tended to create their own fit by detailing the MBC they knew, making visible some of their hidden realities.

As a precursor to project findings, I first noticed the importance of this sense of belonging during the recruitment phase of the research wherein layers of doubt and uncertainty around MBC and belonging were beginning to be disclosed. All the women who responded to recruitment materials (see Appendix G) had a breast cancer. However, not all of them had cancers that were stage 4, advancing, or metastatic. The uncertainty around belonging that was disclosed by the women during these conversations was startling. Even after productive discussion of recruitment requirements, it was common for women to be uncertain about the fit of their cancer with my project goals. It was just as frequent for them to be uncertain about their relationship with mortality. We had rich discussions about the specifics of what kind of breast cancer they had (such as stage, hormone involvement, and prognosis) and about the fit and disconnect with the advanced breast cancer definition for my project, and the ways the women themselves had come to describe their illness that worked for their lives. All the women I spoke with were seeking out people open to hearing their stories and who were knowledgeable about MBC. Echoing sentiments of other women who contacted me, Kristin said she appreciated the focus of my project because “it feels like there’s nobody listening and there’s nobody to talk to.”

‘Survivor’ was a social category that was a problematic fit for the women. None of them identified as a cancer survivor, and each actively contested it in her own way. Five women rejected the notion of survivorship outright because it did not resonate with how they thought of living well with MBC. Mildred stated emphatically, “don’t call me a survivor…. I think it defines you when you say well, I’m a cancer survivor. How can you say that? You’re either alive or you’re dead.” She went on, “it just doesn’t fit me. I hate the word. I think maybe because then it changes people’s view of you.” Most women also disputed the various terms used to describe survivors, but for different reasons. Simone spoke about the role bravery plays in survivorship, “people say, ‘[y]ou’re so brave. How do you do it?’ I’m like — you would do it [too] because I’m not brave. I don’t know how to do it. I’m scared. Sometimes I cry in my bed.”

The women in this study pointed out that the social categories applicable to MBC were in flux. The women negotiated the effects of both advanced breast cancer and cancer survivorship. In a world of greater cancer acceptance, the women I spoke with still regularly experienced MBC as a marginalized experience. A key difference with the women in Gray, Sinding, and Fitch's (2001) landmark study on women living with MBC in the face of the new phenomenon of breast cancer survivorship, was that the women in my project encountered entrenched survivorship. For example, survivorship now has a wider reach and, at times, could enfold MBC as part of women doing well with breast cancer. Another difference was how the MBC known to the women in my project rubbed up against the multiple permutations of extended breast cancer survival today. For example, they spoke of their frustrations with stage 0 breast cancer and how this scientific advancement could create a misunderstanding that breast cancer was a neutralized disease, not a threat. Similarly, key informant Lisa Leger (who in our conversation agreed to be identified in this dissertation, personal communication, April 12, 2016), a health consultant for the Parksville Pharmasave on Central Vancouver Island, spoke of how people tend not to understand cancer stages. A reality, she said, was compounded by how "the breast cancer pool has become muddied" to now include women diagnosed with very early signs of breast cancer that may or may not manifest into serious disease.

There was turbulence in belonging generated by how the women's outward physical appearance did not necessarily align with what was going on in their bodies. At the time of our interviews, none of the women looked as if they had a life-limiting illness or end-stage breast cancer. Looking healthy was true even for the few women who were recovering from invasive surgeries as well as for the few who were participating in clinical trials of aggressive therapeutics. Mildred said:

> But I always have cancer. They (those in her life) have a hard time understanding that I always have cancer. Even if it's not visible to anybody, nobody can ever say that it's gone. And that normally shocks people because I don't think most people have any clue what metastatic cancer is.

An outcome of such tension was that the women felt uncomfortable to one degree or another with the disconnect between how their body appeared to outsiders. For example, Lorraine spoke of looking well and wondering if people thought she was a “fraud” for living so long.

Another aspect that challenged the women’s sense of belonging was how suspended MBC turned out to be a challenging experience for them to put into words. The women spoke of ethereal symptoms, ongoing revisions to health status, divergent healthcare information, and a general lack of understanding about advanced breast cancer by others. Echoing with other women’s accounts, Kristin said, “I don’t know what to call myself, because I was metastatic and I think, but I’m not. But I sort of still am.” A challenge was how to speak of a cancer at all, let alone a cancer outside of expectations so that they might better connect and communicate with others. It was common for the women in daily life to encounter both an understanding of MBC as only an end-stage disease and of breast cancer as being a well-controlled disease. Kristin discussed her concern about the new entanglement of the breast cancer awareness movement alongside the idea of a stage-0 breast cancer stage, “[s]o people are thinking that’s what breast cancer is now [a disease found long before it spreads] and nobody dies from it.”

In trying to speak of their MBC, the women often re-purposed common phrases. For example, Simone used the word “relapse” to describe occasions when MBC disease was indisputably active and to distinguish such occasions from an ambiguously defined phase of bodily activity that might or might not be cancer-related. In using “relapse,” Simone did not mean that at other times MBC was gone, dormant, or did not have a presence. “Relapse” merely referred to actual activity, with MBC in full view, for once.

The women in this study discussed how gradations of “secrets,” “stigma,” “taboo,” and “discrimination” created a churning of belonging and exclusion, inclusive of problematic silences. Speaking of their lives in smaller communities, the women noted that MBC is still primarily associated with death and is usually a socially isolating breast cancer. For example, they spoke of encounters where it was awkward or challenging to have a breast cancer that did not conform to widely held expectations of that socially accepted illness. Regarding her cancer support group, Simone said that when encountering women with early-stage cancers, she would say, “I can’t talk to you. I can only talk to people who have stage 4, unfortunately. I’m jealous of you.” It was also common for women to be navigating silences. Kristin said, “I just find it sort of, taboos all over the place, you know, to talk about losing your breast. People don’t want to talk about that, you know. So I find it’s [MBC] in many different areas.” For example, she was the only stage 4 cancer person in a support group she had hoped would be a resource and how, at the end of a course of treatments, many people in her life acted as if her cancer was over. Daily life was such that for women, sometimes silence was the language most readily deployable. There were social circumstances where they chose to hold back details or stories because they had a health condition that could make other people feel uncomfortable. Speaking directly to the stigma around both death and cancer, Simone said, “it’s hard to kind of look death in the face and explain that to someone that’s just complained they got a bad haircut” and “it [MBC] scares people a lot to kind of describe exactly what I have to them, so I tend to not.” Silences were not empty spaces for the women; for example, they used this silence as a site to express the complexity of their emotions and their decisions not to talk.

The women I had conversations with spoke about living with underlying social isolation. There were lingering uncertainties for the women about their medical status. This uncertainty led to questions of fit with other people who had a serious illness. Living in smaller communities meant they had questions about how they fit with the few available support groups in their areas, whether offered through local non-profits or ones that were more informally organized. For example, Meredith spoke of how her recent respiratory issues had caused a change in her relationship with her walking group for cancer survivors. She said, “I used to walk regularly with the group, and now, if they go, I might walk just a short distance with them. So it brings into focus the fact that I’m not like them anymore.” Her account speaks to how, although isolation was highly individual, it was common enough among the women that it signalled a divide between what they desired for healthful living and what they might be able to achieve.

One of the ways the women addressed uncertainties about belonging was by being creative with their existing community resources. In this project, it was evident how intensities of belonging could disrupt living well. Affirmative belonging was something the women sought out, and if found, it often emerged in unexpected ways. After deciding that her local breast cancer supports were toxic for her, Morven found alliances with the local COPD (Chronic Obstructive Pulmonary Disease) group that she had a prior connection with and that offered support from other women living with an ongoing illness. Uncommon in this project, Adrienne cultivated belonging via the depth of her pre-existing connections with immediate neighbours. This support included offers of rides to the BC Cancer Agency, dog walking, and meals brought to her house. Adrienne incorporated this local support into her network of belonging that was extensive at the time of our interviews and was a poignant counterbalance to any potential social isolation she might otherwise have experienced.

Another outcome of uncertainties about social fit was that the women in this project created refuges of belonging where they named the terrain of their illness. The women spoke of how part of daily life were questions of who they were, whether from themselves or others. In response, they worked to delineate where they were with MBC and who they were as someone with health concerns today. A common way the women nurtured belonging was that they formulated their own working definitions of MBC (see Table 6.1). For example, Janice said that when it comes to describing her cancer, she has gone with, "[t]his is going to kill me, but not yet," and Simone said, "it just lives in my blood." Kristin wrote down the elements that collectively were a statement of what it was like to be living with MBC and how she wanted others to consider her as someone with MBC (see Table 6.2). The women also built belonging by seizing on opportunities to reframe and articulate what a good health status was. For example, Adrienne and Morven boasted of how their oncologists had commented on their "big files." These paper medical files, thick with reports, were a tangible sign of their longevity. Both spoke of how defining who they were by these files provided a new sense of belonging that fit with who they were now with MBC.

Table 6.1 How Women Define Their Disease/Illness to Others — Excerpts from Interviews

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I define it as furious, but stable. Having said that, I think most people have no idea what I mean by that. I don't think an average person knows what metastatic disease is. So, I do try and educate them [including that she is still in active treatment] … it comes back to, it's very serious, but currently I'm stable and I'm fine. (Kristin)

… it seems to have become chronic almost and that I wasn't expecting it … it's a strange way to live because if you're not over-exerting, you feel pretty normal. But if you do, and it doesn't take much to over-exert, then you get short of breath and diaphoretic and you

realize that you've got something. But other than that, it's a pretty normal existence. But, I would think if it goes on too long, it'll get kind of stressful … I won't be able to do as much for a long period of time. (Meredith)

Way I define it is that I have cancer that, it just lives in my blood and I treat it so that it doesn't pop up. And when it does, I go bald again and get chemo. But, I always have cancer. They have a hard time understanding that I always have cancer. Even if it's not visible to anybody, nobody can ever say that it's gone … and sometimes I compare it to diabetes … it is worse than diabetes, but it's that same kind of idea where you're giving yourself insulin and manipulating your body all the time. (Simone)

It has been an interesting journey, over which I have had little control except to take the medications. I don't remember who told me, but one of the doctors said, 'cancer has got you.' Cancer has got me, ok. It is part of my whole body, however I am extremely fortunate, because I am not in pain from it …. to me it is not fatal, it doesn't feel fatal although it is a fatal disease … I am very aware that it is fatal. In my mind I wait for the change in the cancer, where it will strike again. I get emotional when I think of when that will happen, my journey is going on another step and it is probably towards death. (Morven)

I would use the word 'chronic'. It's not going to go away. I probably wouldn't have used that five years ago. I would have used it [breast cancer] as curable. But now it's chronic … well it's going to kill me eventually, but eventually … this [MBC] is just something you put up with. I have friends who can hardly move with arthritis. It's just something you put up with. (Mildred)

I just say it's the liveable cancer. And I think I'm pretty much a definition of living with cancer, that term. I've heard it said that a cancer cell doesn't know when it's supposed to die, so it just lives and keeps dividing. I try not to have a negative feeling towards it, because it is part of my body. They are my cells, I made them. And they live with me now, as long as they behave themselves. (Toni)

I would say it is life altering, but not 100 percent for the bad. It's like standing on an area rug and someone whipping it out from underneath you. It's a freefall but not necessarily in a bad way … like everything has been altered just that little bit … I thought it meant end of life … now I know what it means. It's a life-long illness that will be forever there on that shoulder … if I knew 22 and half years ago [her first brush with a cancer] what I know now, I would be absolutely amazed I'm alive. (Cynthia)

I talk about it more on a spiritual kind of basis. So, I don't talk necessarily about it … rarely do I ever talk about longevity with anybody. Today was probably the first time. I'll say [something like] well this treatment is going to last this long and this treatment lasted this long ... I'm not going to think with those sorts of parameters [cancer prognosis], because it's about my life. So, I'm going to try to say, "well my life's busy." So that's the thing for me is that I talk about it more from a holistic point of view, not from a medical or about the treatments or anything like that. It's more about just how I'm living. (Adrienne)

> *I call it metastatic breast cancer. However, most people don't get that, they don't understand that. So, if somebody presses me, then I tell them it is stage 4 … (later in the interview, she continued) I have breast cancer and it's a chronic condition. I'm not admitting anything more than that … in the back of my mind, I still know that at this point in time, that it possibly is a death sentence, but I'm trying to think of it as just a chronic condition, that is changing. It could kill me. It could change next week … I could get really sick. But at this point, I'm just going with it's a chronic condition … there's still way too many women dying of it [MBC] every year, but they're making steps every day [in research], so I'm just hoping that I'm on the clinical edge of those steps. (Diane)*

> *I say, "Well it's like a chronic disease nowadays." That's what I would say. It's like having a chronic disease, like you have ... I was going to say Tourette's. It's more like Lupus or whatever. People often live with these diseases, right? And they get treatments for them and you carry on as long as you possibly can. That's how I say. I wouldn't say … I find it a death sentence and on August 7th, 2018, I'm going to die. That's my last day on earth or anything. No. I'd say, well you have to take it a day at a time and hope for the best … you just have to hope that they get the right treatment that works well for you and doesn't have many side effects. (Janice)*

Table 6.2 "What it's like living with (suspended) metastatic breast cancer" by Kristin

It's the worst news you could ever receive
It's extreme stress
It's disbelief
It's a series of mini marathons of treatment and recovery
It's isolating
It's a financial burden
It's a disability
It's a constant state of unknown
It's emotionally draining on the patient and everyone tied to the patient in any way
It starts as a full-time job and then becomes part-time
It becomes normal
It is not understood
It is not talked about
It is taboo
It's living with invisible scars
It's a language that only those 'in the club' speak
It's always somewhere on your mind
It's constantly feeling unwell
It's a burden on the health system
It's a reduced quality of life
It's constantly wondering

It’s having many questions with no answers
It’s having many side effects
It’s rarely having a good night’s sleep without a ‘sleeping aid’
It’s having relentless hot flashes
It’s rough on a marriage
It’s teamwork
It’s a community coming together
It’s painful memories
It’s Post Traumatic Stress
It beats you down
It makes you strong
It becomes your life
It’s cut, poison, burn
It’s a story to be told and heard

Body Signals: Deciphering the Body

Living with suspended MBC the women entered a strategic relationship with the body, because of the need to decipher ill-defined body signals or sensations that arose. It was common that the women experienced an array of ambiguous body signals. At the same time, they recognized that when decoded, these signals could be one of the better chances they had to navigate their health. A puzzle the women encountered was whether the signals were a register of ageing or cancer. Complicating such efforts was how most of them had been healthy before diagnosis and navigating a seriously ill body was new. Also, with some of the women living with MBC, this was the first time in their lives they had sought to attune to, or had been attuned with, their bodies. Mildred said, speaking of her life-long propensity to plan, “[e]very morning I’ve woken up and thought about my day, always, for my entire adult life. But I’ve never thought about how my body’s going to manage.” She said she had become, “very aware of my body and how it works.” When I asked Simone what an average day might look like, she said she had no concept of an “average day” between mid-life ageing and cancer. She said:

> I don't know how to answer that because it depends on how the day is. I wake up in the morning, I lay in bed and I think about what I'd like to do today and then I think about how I'm feeling and then I get up.

Living⇔dying with MBC mirrored the hard-to-understand bodily signals the women experienced pre-diagnosis, their first indicators something might be amiss health-wise. For all the women I had conversations with, cancer did not arrive well-announced, nor was it something most of them had really thought about at first. It was common for these early signs to be in the form of vague body signals, such as activity-disrupting shortness of breath or a persistent backache. Signals that for the women evoked curiosities and grew into questions needing medical inquiry. These signals were a bodily experience that each of the women would look back on when they considered how to approach their now suspended MBC, which was far less distinct than the active disease that they had known for a spell.

Encountering MBC as a mysterious illness, each of the women in this project refined their attentiveness to their bodies, in what could be called embodied terrains. These terrains included their baselines, their good days, and their bad days. Mildred spoke of her embodied orientation to her body concerning her troublesome symptoms. She said, MBC "doesn't stop me from doing stuff. I find a way to do it anyway." She continued, "I actually still do ignore [the symptoms] a lot. I do. And that's partly how I continue on. But I'm more aware of trying to do something if I'm not feeling the way I need to." Now in a routine with her illness and body, Kristin spoke of instinct:

> And he [the doctor] thought there were two different lumps, which I never agreed with. And this is the intuitive part, that you know your own body. I never thought there was two lumps. So, when he kept referring to this, he said there was one close to the surface and one farther in, I always found that strange.

The women I spoke with discussed how signals from the body were by default complex, and not easy to understand. Kristin said, “you never get to have a cold or just have the flu. There are all these extra questions.” Similar to what other women talked about, Cynthia said making sense of ambiguous body signals was made harder because she had two warring factions inside her. She felt as if on one shoulder was her “logic,” and on the other was her fear of “recurrence.” For example, she spoke of the time she had seen her general practitioner because of foot pain, “so you know, it’s just logically I knew I had dropped something on my foot. That’s this side. And this other side’s going, what happens if you get a recurrence?” And this “back-and-forth” Cynthia spoke of occurred within a greater ambiguous context where she knew, “it [MBC] never goes away. It’s mute a lot of the time now, but there’s still, so much body ache that they can’t tell me why.”

At the time of the interviews, many of the women were participating in advanced therapeutics as a response to bodily signals. These women discussed how the resulting fatigue could give living⇔dying a defined presence. Undergoing an extended course of chemotherapy interspersed with multiple radiation treatments, Diane said, “[y]our energy level is just not very good. I think for about two years I’d be out in the garden and I’d be raking for ten minutes; I’d be sitting for ten minutes.” Rather than risking that Diane’s energy levels might become even more limiting, she and her husband changed their long-term retirement plans to accomplish a shared life goal of travelling. For these women, navigating the paradox of advanced therapeutics that would possibly extend life came with restrictions on how one could live now.

Many of the women discussed how they lived with and oriented toward fluctuations in their energy levels. Fatigue was the most common body signal and the predominant sign that they were still living with a cancer. Some women discussed how the restrictions for low energy levels took the form of occasional "spells," while others discussed how the restrictions defined their embodied milieu. The women tracked energy levels as a rough sketch of their illness-related limits. Mildred pointed out that a vital part of the MBC puzzle was how "you know how to spend your time or your energy." The women in this study all had a pragmatic sense of the energy they had to work with and of what it meant for them for the next few days. There was a sense of a 'planning loop' where they continuously monitored their energy levels and organized their lives around them. Of course, this meant planning for ways that the fatigue disrupted those plans. Mildred said that MBC:

> slows me right down. No matter how you look at it, it slows me right down. I had to quit work the beginning of May. I loved my job. But you have a timeframe and you have energy and if you use the energy up [on] one thing, then you have less for something else or it becomes more difficult. What I was doing was fighting my way through everything else on the days I worked.

In contrast, Meredith put to work her introverted proclivities for energy conservation. For example, she made use of her joy of reading while making decisions not to go out so often. For the women, paying attention to their body's signals sometimes eased their fatigue. However, their work of monitoring energy became a way that MBC had a presence in their daily life.

Being in dialogue with their bodies, particularly around energy levels, could lead to the women embodying the contradiction of feeling well or normal, while at the same time, realizing that they were a product of illness management. Meredith said:

> it is a strange way to live. Because when I'm just here or just walking for the mail or around, I'm fine, but if I do too much, I get very diaphoretic and tired. So, I know I can only do so much, but when I'm not doing too much I feel perfectly, pretty normal. So, it's a difficult way to live.

Contrary to how it might seem to others, Meredith said her life “isn’t really a normal life” and “you can only do small things.” Her life was “more compacted. It’s short things.” She had a tailored rhythm of living entangled with the monitoring of energy. Likewise, Morven, who thrived on her community connections and was regarded as a social butterfly, said, “I notice that my world is getting tinier. But that’s why I watch the news more because it is bringing in the outside.” Watching the news was but one small adjustment she made to reduce the effect of a shrinking world. Like other acts, these were unknown to others.

For the women in this project, thinking about ageing and its effects became an useful strategy to decipher body signals as to whether MBC was having an impact on them at any given time. It was common for the women to wonder whether the body signals could be indicators of active MBC or were aspects of ageing. This doubt over what was causing the body signal tended to occur early on while living with MBC. For example, with Lorraine, “I'd get these twinges in my hip. But my mom had bad knees and my brother had a hip replacement, so I thought, oh well, it runs in the family.” As if echoing other women’s comments, Kristin said that in reading her body,

> ... there's so many things that I don't know because at the same time I'm ageing. So, am I feeling that way because I'm ageing, or am I feeling that way because of the cancer or my drugs?

The women ranged in age from their late thirties to their late seventies. All of them spoke of possible age-related shifts in their bodies. The body signals they were reading included those signs that might indicate entering middle-age or advanced senior years. Sofie, who was in her late seventies and was an active West Coast senior, spoke of how “frustrating” her newfound physical limitations were. Part of the difficulty was sorting out which sensations were related to ageing and which were related to MBC.

> We all age and you start getting more aches and pains … that’s the difficult part is to find a balance, not to worry too much about [MBC] and think that every little pain you get is cancer. But, at the same time, you have to pay attention to it, if it persists, because maybe it does mean there’s something.

The longer the women were living⇔dying with MBC, the more they integrated deciphering body signals into a larger project of illness prevention alongside ageing. Morven, who had lived with MBC for ten years, spoke of how most of her illness workload now revolved around several conditions of ageing. For example, when I met her for our second interview, she was going through rehabilitation for carpal tunnel surgery. The side table by her chair held soup cans and small dumbbells that were part of her daily strengthening routine. She spoke of how rehabilitation was particularly important because she could live for many more years. However, such projects of working with ageing had limits because it did not mean that women could identify signs specific to ageing. Morven spoke of how after consulting with specialists, her first impressions were confirmed when she was told it was not possible to tell whether her arthritis was an adverse side effect of cancer therapeutics or part of the ageing process. Darlene was one of the women in this project who engaged in tailored measures to control her current cancer concerns and helped prevent future health complications. She said, “I’ve got to go through some surgeries and stuff just for preventative purposes. I have to get my ovaries, removed which will be done through a laparoscopic procedure and probably my right breast taken off as well.”

An encounter with MBC as likely advancing could significantly alter how the women engaged with their bodies and how they framed MBC going forward. A detailed example of this kind of “cancer scare” comes from a discussion I had with Morven. She spoke of a cascade of events that occurred after a routine scan of her hip revealed what she called “the shadow,” referring to a shaded area of bone that should have been white if healthy. The hip in question was her surgically repaired hip that had broken years ago because of bone metastasis. The test result did not fit with how she had no symptoms for many months and had no reason to wonder whether her cancer might be active. Over a two week span and across different healthcare practitioners, Morven was jolted from being told she had a "controlled, non-progressing breast cancer" to a "probably palliative" cancer to "having a non-problematic fracture due to the ageing process and the nature of her hip repair." Morven tried to rely on her relationship with her body while navigating uneven terrains of the cycle between uncertain news, no news, revised news, and new news. This event was an abrupt end to a months-long stretch of calm for Morven, and it did not mean a simple return to the MBC she had mapped out before. She was vigilant to body signals for the next couple of months and became more suspicious of her body when it returned to being silent.

An unusual, yet highly practical, example of being in dialogue with the body and deciphering bodily signals was paying attention to bodily sounds. Meredith had ongoing issues with her lungs. A way that MBC could be visible to her was through sounds her breathing made, while there was still a degree of ambiguity around specifics.

> I do get short of breath if I do too much. Plus, I get this kind of whistling, different sounds, I guess in my lungs? I don't know. When I was walking yesterday, I thought, what kind of bird is that? And then I realized it was me on expiration … making this sound. What would that be?

Tethers: Untangling the Categories of Medical Status and Labels

The women in this study routinely encountered biomedical categories and descriptions of health that constricted, troubled and/or occluded their current reality of living⇔dying with MBC. They discussed how ongoing or "stable" MBC, as Deirdre referred to it, did not conform to what the women had first been told about their life-limiting illness by practitioners and the typical categories applied to MBC. Given the evolving status of MBC in their lives, by the time of our interviews, the women had a bundle of institutional categories or other medical labels delineating their illness. For example, many of the categories associated with advanced breast cancer clung to the women no matter whether or not the women claimed them. Each of the women wanted to name their condition, yet they also resisted many of the names ascribed to them. In other words, they were living with the legacy of life-threatening illness descriptors attributed to them, particularly from their early days with MBC, while seeking out how to live with their ill body. The categories ascribed to the women worked as tethers that held them to a certain kind of representation of MBC even though that category may be undesirable, outdated, and/or disembodied bodily identifiers.

The women in this project detailed ways these tethers worked. Individual categories could twist their day-to-day life into being all about cancer, which meant they were "defined" by the disease, as Dianne said. It was common for the women to try to loosen the tethers of ill-suited labels, by using their own embodied knowledge of living⇔dying. However, these health categories were different from both the sense of belonging they mediated and the body signals they monitored. For these women, being tethered to more rigid descriptors emanating from biomedicine was problematic because of how the monikers were generated and sustained in healthcare systems. By untangling these tethers, the women shifted the terrain of MBC to something more amenable to their bodily existence, even though, suspended across the living⇔dying boundary. Because of the unavailability of distinct waymarkers, in untangling these tethers, the women frequently used trial and error to refine their knowledge about how the categories shaped their lives.

The women's engagement with the categories, phrases, and labels applied to them became more sophisticated as their knowledge of their MBC grew.

For the women in this project, the diagnosis of an advanced breast cancer reverberated throughout their daily lives. At any time, the gravity of the medical language and navigation of their illness demands during diagnosis. shaped how the women were connected to these labels. Cynthia was one of the few women to receive a formal prognosis rather than a more general comment about possible futures. She spoke of how that legacy remained:

> Cynthia: Certain words scare us. I remember the first time I was told I was palliative.
> Interviewer: Did you know what it meant?
> Cynthia: No. I thought it meant end of life. And it's like, hmm. Now I know what it means, right? It's a life-long illness that will be forever there on that shoulder … just [as] the words we hear sends us into a spin until we find out the correct meaning of the word.

This disclosure of her encounter is an example of an underlying tension between normative biomedical categories ("palliative") and embodied knowing ("correct meaning").

Mildred was one of several women who were still confronted with the severity of their diagnosis and associated limitations because of having to still see a cancer care professional. She said she goes about daily life within the parameters of "you're living in the world of cancer, but you're not really physically living in that world." Her goal was that of living, not merely being "kept alive." Troubling her goal was that every time she saw her oncologist, she faced comments about how she was technically dying from cancer. For example, the poignancy of death as brought to the fore when he said to her, "you do realize you're not going to live?" Kristin said that every three months, she sat down with her GP to review her oncologist appointments. At each of these meetings, her GP would rely on the cancer agency letter, “and that always starts with your diagnosis.” She would be pulled out of her daily flow, and she would reconsider anew, “who is that person” in the medical chart with that diagnosis and history, and “how am I living?”

Sifting through contradictory phrases that healthcare practitioners applied to them about their breast cancer status, became part of the women’s lives. Prominent examples of these phrases discussed in this project were: “bone cancer,” “cancer-free,” “a special case,” and/or “cured.” For a few, there was also “palliative.” Simone spoke of how she thinks about her cancer after it had been discovered in several places in her body: “I think of cancer differently now. … I know it’s not one whole thing. It’s a bunch of different things.” Kristin was one of the women who rejected “cancer-free” as applied within biomedicine and elsewhere. She rejected her oncologist’s declaration because metastatic cancer was not something “done, and you’re fine.” One of the ways MBC was evident in Kristin’s daily life was the ups and downs of post-traumatic stress syndrome. She also spoke of how being a “special case” was not a “good thing,” and although that term had evolved into something of a term of “endearment” between her and her oncologist, she “knew what it really meant.”

Part of the contradictions generating the problematic phrases being applied to them was how the women’s embodied status was in flux and how there were differences in the practices of the healthcare team members. There was also the effect of smaller communities, including how the women discovered that there was no guarantee that their local healthcare practitioners had comprehensive, up-to-date knowledge of MBC. An example of all of these factors coming together is in Simone’s discussion of a medical encounter: “wow, what a difference in these two things [medical opinions]. One doctor’s like, pretty much you're going to die immediately and one doctor's like, maybe that was just your body [the way it is with cancer]."

The longer the women in this project lived, the more medical descriptors they had to untangle. Entwined with the number of descriptors, was how quickly biomedical technologies were changing the parameters of MBC itself. Cynthia had lived with advanced breast cancer for so long that she carried with her historical knowledge extending back decades to the late 1990s, coinciding with the start of breast cancer survivorship in Canada. She was a living example of how medical understandings of breast cancer stage classifications have changed. For the same presentation of cancer, she knew herself by both the older designation of stage 3B and the current classification of stage 4. The other women in this project were either on their way or becoming well-established in a landscape that Cynthia now new better than most. Cynthia's account and comment about the medical language I shared earlier about "finding the correct meaning of the word" discloses how the women in this project might need to navigate how they did not necessarily have a static advanced breast cancer diagnosis, and they no longer lived with a life-limiting illness that had a fixed direction.

Meredith was the one woman in this study who been formally designated by healthcare as a palliative client. The untangling of the tethers binding her to these medical categories of MBC played out in specific ways. After her diagnosis resulted in placement within a community care treatment program, she gave away clothes according to changes in weight, put her children's names on several significant items, and gave away household possessions she deemed surplus or unnecessary. At the time of our interviews, she lived amongst multiple physical reminders that she kept living longer. For example, between her cancer no longer advancing and good pain control, she had gained weight and she now had few clothes that would fit her. However, she could not discern whether she was medically stable enough that she could confidently replenish her wardrobe. Her lack of clothing affected her decisions on whether to go out of her home. This dilemma was one of the ways that being "palliative" manifested in her daily life and troubled her goal to restore her independence.

At times, indistinct manifestations of MBC were a barrier to the type of care the women needed. Thus, for some women, the untangling took the form of advocating to be included in a biomedical category. Living in smaller communities with suspended MBC, the women encountered issues with healthcare access where their diagnosis and medical needs did not fit with local healthcare services. Part of life in suspension was the need to educate healthcare professionals about specific MBC treatments that were less common outside of urban centers. And they had to advocate for those treatments. Both incredulous and annoyed, Lorraine spoke of trying to obtain a therapeutic prescribed by her oncologist at BC Cancer Agency:

> So, I would go up here [local hospital clinic] to pick it up, and they said, "We don't have a store. We'll have to order it." And I said, "well, I have to have it for tomorrow [she was medically due for this treatment]." It just became a nightmare. So, my husband phoned somebody at the hospital in charge, [he] spoke to her, and she said, "well, we're just not equipped for this sort of thing here." I mean, how hard is it? They send a prescription up from Victoria.

Such friction was part of the tapestry of uncertainties when MBC did not neatly fit acute categorizations of the disease. As well, the communities the women lived in could become a constraint when they had nonstandard medical needs.

Similarly, just as some women faced barriers around their medical needs tending toward being more chronic than acute, the women in this project needed to be active healthcare consumers, rather than static medical patients, if they wanted workable cancer care over time to optimize their wellness goals. The women I spoke with varied in how willing they were to engage available healthcare services, under which circumstances, and for how long. However, living with a suspended form of MBC, the women were always subject to being misunderstood within the healthcare system. After one particular round of treatments a few months into having MBC, Kristin was still "sick" and "nauseated." However, when Kristin contacted the cancer agency for assistance, she was told, "you're not in active treatment, you're cancer-free." Here, she found herself facing the quandary of having cancer-related symptoms yet needing to find a way to get medical assistance. Her cancer-free status kept her in the category of a medical patient, and for her to feel better, she needed to assert herself as a health consumer needing care.

Enduring: Horizons of Hope and Possibility

In this project, living with suspended MBC was a distinctive kind of endurance where the women would regularly seek out, cultivate, and keep focused on the horizons of hope and possibility. However, endurance and hope were not so simple; endurance for the women was a day-to-day challenge, given what women might hope for kept shifting and with it horizons of hope. For example, a husband I spoke with described a nascent hope that he and his wife shared because she was now thriving as a patient accepted into a clinical trial, which came after months of her being on a debilitating chemotherapy regime that, at the time, had been *the* cutting-edge approach. As discussed by the women in this study living⇔dying with MBC, enduring was about more than the passing of days and continuing to be alive. Months into having MBC, endurance for the women was an inherently relational process: they prioritized elements of living that were inseparable from their grasp of hope. However, this hope was not the kind typically associated with normative cancer survivorship. The women's accounts featured a kind of hope imbued with affirmation. Affirmation, in this sense, means assisting in the creation of the life that the women wanted to live, the life that they most desired. Within these affirmative interactions, hope fueled by vitality and practicality, created a situation so that the women could endure living⇔dying with MBC (see Braidotti, 2011b). Theirs' was a type of hope that was a "way of dreaming up possible futures" (Braidotti, 2011b, p. 237) for themselves and those that were dear to them. All of the women I spoke with embraced how theirs was an illness with possibilities for healing and extended life. Their daily lives exemplified how their future lay on a horizon of how they used an affirmative brand of hope to generate possibilities for living⇔dying with MBC (see Braidotti, 2011b, p. 237). Their futures compelled them into action. For this analysis, I am using 'enduring' and 'endurance' to highlight the process of how affirmation happens and how it is part of the hope women embodied despite the evolving nature of the obstacles they encountered.

There were two sub-resonances of enduring that were particularly evident in the women's accounts of living⇔dying with MBC. First, given how daily life for the women was suffused with possibilities for abrupt changes in the horizon via a dynamic range of emotions, they engaged in small practices of *mediating* hope. Such practices include the concrete, often pragmatic, acts where the women incorporated a specific notion of a future for themselves into their day-to-day life. For example, Mildred had a pact with her general practitioner that if she ever needed pain medications, she simply had to ask, and he would make sure she had what was needed. Not necessarily noticeable as acts of hope, these practices included resistance to various pressures they faced in living with ongoing MBC, as well as, short-term denial of ill-fitting stories that could derail their drive toward enduring. Second, the women cultivated an orientation toward *pathways of living*, including life-prolonging medical treatments as a sustainable strategy of embodying and enhancing living. MBC is a serious illness with a plethora of new treatment options becoming available in a speedy succession. The women were actively engaging with pathways of living that held a variety of possibilities, as part of the hope embedded in their daily acts. Through these two types of enduring, women in this project cultivated practical hope and became their own hope at times through occupying possibilities of stable MBC.

Mediating Hope: Small Practices

Hope was very much part of the women's daily lives via pragmatic and realistic actions that they engaged in. In mediating expectations, the women developed small practices of hope through various means of understanding and experiencing MBC. Inseparable from the day-to-day, these small practices were seemingly mundane strategies and affirmative ways for mapping out bigger futures (Braidotti, 2011b). For example, when creating a mind-map of what she was grateful for, alongside global ideas about community, clean air, and creativity, Kristin included elements that were part of what I am calling small practices of mediating hope, such as swimming, honey, bicycles, and meditation (Appendix X). Small practices were part of how MBC was not a sprint, and as Diane says, "it's a marathon." For the women, hope was often realized through many little steps that made up a long journey. Living⇔dying with MBC may be a life of mediating persistent uncertainties.

Yet, it was through seeking day-to-day practices of hope that the women found an endurance that enhanced their lives.

The women in this study often challenged the ways people told them to think about their life-limiting illness. Instead of sliding into a positive emotional state that people usually insisted that the women needed, they crafted their own embodied practices to engage the world constructively. Simone refuted the notion of needing to be positive all the time. She constructively inverted this positivity. Rather than having a "positive attitude … it's more like how do I maintain my denial?" For her, denial was a small and reliable practice of hope. Simone's stance of "I'm not dying, sorry" was a bridge back to the reality that beyond cancer, she was a mother with young children and an "extremely stubborn person." Toni, a professional artist, put her independence and imagination into refining her take on how to endure with MBC. Toni said that "the other side of medicines and surgery was the power of the mind," and "the mind can heal if you are in the right mindset." For example, she could find stability in "shaking it off":

> You just learn to roll with it and focus on your day rather than the future. And when I get told something that is intentionally scary, I just walk out of the doctor's office and just have a bit of a scary few hours. Then you just sort of shake it off and get back to your day. And then a better perspective settles in, and you carry on, As long as you're not feeling sick, I can do that. I can just shake the doctors off, that's what I call it. Shake them off.

Toni was also aware that shaking it off takes effort and uses up emotional energy. She worked at blocking whatever might "drain" her energy while courting whatever energy might be a boost, Like Toni, Kristin guarded her energy against negative emotions. To do so, she eventually realized that a generative way to live was to do "what makes you happy and be done with all the rest." This phrase was a mantra she presented to me on a mini-poster that she created and kept in a place where she could easily see it. Her goal to be happy was steeped with intention, nestled within her well-developed sense of morals and ethics.

It was also common for the women I spoke with to see their small practices of hope as types of resistance. These small practices included ones directly contesting or thwarting pressures that might disempower them. The most common of these practices was some variation of choosing *not to know*. Cynthia countered the "difficulty" of how "there are no answers" and "everything is grey" by being selective about her information needs:

> It's like, do I lose my comfort zone and go for it and find out if I'm triple-negative? I don't like choices like that, so I've chosen not to. I've chosen to stay in my comfort zone.

Part of an effort to keep on her own path, Simone insisted on no "conjecture":

> So I have a kind of rule checker if I meet any doctor. Before they start talking, I say, "Here's the deal. I don't want you to tell me any statistics. I don't want you to tell me my prognosis, whatever that means." … I want to know what is going on with me. I want to know what we're doing for it. And I want to know if it's not working. That's all I want to know.

Likewise, Toni spoke of her "sort of a survival mode mechanism" of making sure to cut clinicians off before they went into detail. She wanted to "just know enough and don't rock the boat too much." Another practice of resistance was curating the resources they relied on. Acclimatized to MBC as a long-term condition, Adrienne now "utilized few resources" of any kind from BC Cancer Agency. Reorienting her life back to feeling like a whole person, she turned to resources of "mind, body, spirituality." For example, at the end of her acute treatments for advancing cancer, she turned to Victoria, BC's chapter of InspireHealth Supportive Cancer Care, to help with building a whole-person plan. Far removed from diagnosis, and heavily engaged in horizons of hopes, Adrienne had a life that was an intricate tapestry of the resources she had curated for herself. She looked forward to her future. Kristin and Simone also oriented many of their actions toward the future, to the degree where they too had a range of resources they curated.

Some of the women in this project used advocacy as resistance. Kristin opposed the belief that living with advanced cancer "should be a secret," so she made herself visible as a person with cancer and made social space to speak of it. For example, she embraced the rare social encounters where people asked her about her illness, and she volunteered for a cancer helpline as a peer mentor for women with various stage 4 cancers.

Resistance also included ways to push back against the financial costs of care. To endure with MBC was to face the financial costs of living longer. The women developed practices of hope as they negotiated the terrain of cost-prohibitive therapeutics. This negotiation included the need to pay for some of the medical treatments that could extend life. Diane said one of her current therapeutics was eight hundred dollars per treatment. Her effort to obtain the name-brand treatments was a source of financial tension while living longer with MBC.

> We had to fight with our extended health care, but they finally agreed. And they said they could cover a lesser brand, but it's not as effective. This is an insurance company. You're not my doctor. I mean I just lost it on the phone, "[y]ou know this is my life you're talking about. I don't want something that's less effective. I want what's prescribed for me."

Simone was able to obtain viable alternatives once the financial costs of some therapeutics had become "detrimental" and strained resources.

As the women's health became more stable, there were more possibilities for incorporating life enhancement activities into daily life. A certainty for the women in this study was that as they lived longer with MBC, their overall health became more stable. At the time of our interviews, the women had enough stability in their health to partake in life-affirming initiatives that were in addition to standard therapeutics and illness maintenance. They also put to work their acquired knowledge of MBC. Unlike their prescribed wellness modalities and mundane routine, life enhancement activities were usually a matter of choice. Because the women chose them, they generated a sense of control, affirmation, and joy. The women spoke of contemporary healing modalities like yoga, nutrition, and spirituality. They also discussed their own modalities and modifications of mainstream options. To retain her love of art regardless of lymphedema, Toni altered her professional art practice by learning new mediums. In place of large-scale painting projects requiring periods of sustained energy, she shifted to found-object sculptures. Pearl was older than most other women in this project, and she spoke of having already had a life lived well. As part of living⇔dying with MBC, her focus was on spending more time with her grandchildren because this was what made her the happiest.

A few of the women went as far as to embark on a comprehensive enhancement plan to navigate their lives, by prioritizing possibilities of living a fulfilled life. Along with Kristin and Simone, Adrienne, filled her days with personal development and life priorities. Unlike her early days with MBC, Adrienne's priorities now included "fun" and "enjoyment." Utilizing her extra time from no longer being employed and building on her extensive research, Adrienne was investing in living life "with my own integrity." She did take up medical opportunities that would treat MBC, such as radical brain surgery. However, even more so than in the past, she would not limit herself and her life only to medical events. In speaking of her strategies on how to live with MBC, Adrienne said,

> A couple of years ago, it would have been more general information, I think. Now I'm looking more into specifics, so I'm doing my own research to see what things I'm finding, you know, so I'm looking more on a granular level of what things are available to me, what things I could be doing to enhance my health.

During our interviews, signs of Adrienne's practices included: the scattering of health-related books around her reading chair that were the recent additions to her library, the animated way she spoke of how her daily walk in the woods benefited her well-being, and the camaraderie she felt with a good friend who had a shared passion for angel guides. I spoke with that friend in a cluster interview. She emphasized how well her friend had always taken care of herself, and she was galled that cancer would intrude on Adrienne of all people. Darlene balanced her need for extensive healthcare involvement with her own "clean living" plan. Each day she focused on what she could do for "prevention." This included having an exercise routine. Her acts of prevention show how she was working towards a future and a life of being far more than a person with cancer.

The ways the women took on small practices of hope threaded the women together and showed how all were exceptional because of their drive and vitality. Collectively, the women were inquisitive, resourceful, educated (whether formally or self-taught) and creative, which fed into these small practices of hope. For example, Morven is a pioneer of breast cancer dragon boating. In response to a recent cancer scare, she said that the frightening experience added another unwelcome layer to the weariness that came from mediating cancer for nearly a decade. However, this was a weariness that most days, she could work around, because she knew about how to navigate physical limits and to keep moving from being a paddler. She said the scare had its place in her life with cancer, but it was not an intrusion on her hopes. An example of how the women were 'exceptional' was that they participated in this project as they saw it as a resource, and they wanted to connect with what they deemed an uncommon source of current information about MBC and a larger community of MBC. Several women spoke of how participating in this project was unusual for them because they do not usually talk to others about their cancer, whether privately or publicly. Project participation for the women could itself be considered a small practice of hope.

Pathways for Living: Orienting to Life-prolonging Therapeutics

For the women in this project, enduring involved creating embodied pathways for living via orienting themselves to the technological advancements occurring around them. Highly aware of medical advancements, the women explored the gamut of therapeutic options they could choose from now, and the options that might be available in the near future. Currently, the women were aware that the most common therapeutics were novel drug therapies and refreshed applications of older drug therapies. The women also explored advancements in surveillance technologies. By creating pathways through knowing these life-prolonging options, the women were able to engage in ongoing adaptations of wellness choices conducive to living more fully. It was usual for the women to associate therapeutics with hope at the start of having MBC, particularly for those more recently diagnosed. For example, Simone was emboldened when her oncologist had told her he was working on getting her to ten years and to seeing her kids enter high school. The women balanced their interest in these kinds of horizons with a practical understanding of how their day-to-day was precarious and how a future was not guaranteed. Juggling complex rubrics of what optimal living was for each of them, the women might or might not partake in available options and sometimes knowledge of advancements alone was what was needed to generate hope. Through enduring, the women exemplified how "renewed generative flourishing cannot grow from myths of immortality or failure to become-with the dead and the extinct" (Haraway, 2015, p. 160-161).

The women I spoke with sustained a network of information that was an ever-evolving counterbalance to the general lack of practical information about suspended MBC. The women often bumped up against partial, outdated, incorrect, irrelevant, or undecipherable information. Moreover, the women discussed that over time they became aware that even if there might be viable resources and information available, they may not be able to locate them. They also believed that they could not truly know what may exist. In the face of such challenges, the women I talked with often tracked technological advancements and evolving choices for living through BC Cancer Agency practitioners or affiliates, wellness conversations in communities and, if they were fortunate, a few allies inside the greater social sphere of MBC. The women in this project had at least one medical professional they trusted and with whom they could discuss navigating MBC. Usually, this trusted person was a general practitioner (GP) in their community. Mildred, who described herself as a planner, regularly worked with her GP because, as she said emphatically, "I have a future. It might not be a long one, but it's a future. Until they [healthcare specialists] tell me that's it, that I'm done, it's a future." Hope generated from advancements was not dependent on whether the women used them, but how it connected them with possible horizons for advanced cancer treatment and progression.

The women in this project could see signs that they were living in an evolving era of life-limiting illness and that women with breast cancer might live longer as well. Framing her opportunities for health in a broader local context, Kristin spoke of how the HIV unit at St. Paul's Hospital, Vancouver, had recently closed and how it was an indicator of a once threatening illness being less so. Three women discussed how molecular technologies had led to a new stage of breast cancer where technically breast cancer was found before it had fully begun. This stage 0 breast cancer was one of the reasons why these women had confidence that their engagement with innovative technologies could result in expanded opportunities for longer life. In terms of what it meant to be a woman with advanced breast cancer today, Janice said, “there’s some women that live with this for 20 some-odd years … why can’t I be one of them?”

The women I spoke with discussed what they considered to be their good timing, given the availability of effective MBC treatment options. Sofie said, “I think [in] the last five years, so much has happened. I’m lucky to get [MBC] this late because if I had it ten years ago, I probably wouldn’t be here.” Janice spoke of how she was “living proof” of how novel therapeutics could mean you live longer and live well. She went on to say, “I do believe now that you can have a relatively productive, normal life living with advanced cancer with the treatments they’re able to give people nowadays.” Adrienne detailed the breadth of therapeutics, open to her and how she needed to prioritize them. She actively drew on both BC Cancer Agency’s way and a more holistic health way from several sources.

> There are so many schools of thought about cancer [treatments]. Well, which do you believe? That’s why I sort of embraced both ways of tackling it, which then led to anxiety because I wasn’t doing all my protocols, keeping them up to date.

Darlene kept engaging “more options.” She spoke of using her experience in training for sports and her expansive range of contacts in Ontario, Texas, and British Columbia. For her, ‘good timing’ was a mix of not only access to cutting-edge procedures elsewhere but also a cadre of social and financial resources to take full advantage of them. She talked about how significant a role M.D. Anderson Cancer Center in Texas has played in her approach to treating MBC. Regarding a new lymph node surgery there, “that is something that has given me a little bit of hope where my arm is concerned.” About the Cancer Centre in Texas, she said:

> Their equipment is so much better than a lot of what we have here, and they were able to determine that without a doubt, [a cyst was benign]. So, of course, you know it gave me some hope.

Hers is one example of how degrees of certainty were a desired commodity in fully living, while living with hope to open up possibilities.

Part of the complexity of embodying pathways for living was how the women mediated the fragility that accompanied pharmaceutical therapeutics. All the women spoke of how these therapeutics could work in unpredictable ways. Toni talked about how good news tended to come with a catch. When her oncologist described how her biological response to chemotherapy was “quite outstanding and extraordinary,” she thought of how “that’s scary too … [b]ecause oh, you weren’t expecting this?” The women also spoke about the biomedical reality that the therapeutics could stop working at any time. It was typical that fear of imminent death was replaced over time by the unknowing of whether there would be a new course of therapy to take the place of their current one when it was no longer effective or whether there would be other timely therapeutics when needed. Janice was one of the women who used the estimated length of her drug therapies as a marker of living and as a practical way to not “give up”:

> I hope to get six more [years], at least. But you know, you don’t know that. And I put a lot of whatever into hope, you know, and faith to get me through. And I think you just have to be positive … [for] the minute … I say “this is hopeless, I’ve had enough,” you’ve met your demise, right?

Part of the pragmatic quality of hope in this project was how the women kept a place in the present for the unknowable future of MBC and worked with that framing for enhanced living. The women in this project tried to ensure technologies did not pull them out of the embodied knowing of MBC that sustained their generative living and hope. Holding fast to an intersection of older medical technologies and contemporary ones, Morven brought over twenty years of living with breast cancer to her ongoing mediation of disease management with the BC Cancer Agency. For instance, she only selectively chose to use Telehealth. Although accessing the BC Cancer Agency remotely worked given where she lived, it did not work given that the assessment was not as comprehensive as a site visit. Her occasional onsite visit offered a more body-aware check-in with how she was doing and what steps might be next. Sofie shared a similar hesitancy about Telehealth, although she primarily found that the lack of intimate personal connection was in tension with her health goals.

An indicator of a pathway for living other women might eventually travel, Cynthia engaged biomedical therapeutics for years before declining to be involved in any structured cancer care. She said of the healthcare system's professionals, "they just threw everything at me because they didn't know" and how "they almost killed me with their kindness." Also, how after years of "holy roller chemotherapy, then you're hung up. You're just left." Being "left" came with a considerable emotional cost. Another unexpected twist in her MBC story is that while she ended up distancing herself from the healthcare system, she kept an eye on what healthcare might have to offer. At the time of our interviews, her body was her primary guide for the desired life. Speaking of her life with MBC today, she smiled brightly and said that life was good, "[y]eah. And enjoying it."

The women I had conversations with also discussed how creating embodied pathways for living around life-prolonging technologies could, at times, facilitate not only their endurance but the endurance of other women with breast cancer. Pearl, who had a genetic form of breast cancer, focused on the legacy that advancements might have for her family. Pearl has a quiet life while living⇔dying with MBC. She engaged minimally with the healthcare system and had few side effects from her one therapeutic. She often spent her illness-specific time educating herself about her kind of cancer. Through her work to educate members of her family and to support future generations she found embodied pathways for living. Adrienne was taking a clinical trial at the time of our interviews, fully knowing that it might or might not work for her. In the spirit of hope, she also said, “I was very pleased to be part of a clinical trial even if it’s just more data for the women.” Hers is one example of how trying a therapeutic could mean endurance was nurtured for women with MBC as collective, regardless of the outcome for her as an individual.

Conclusion

In this chapter, I discussed how transpositions — boundary crossings — are an element of living⇔dying for the women in this project. To have a diagnosis of an advanced breast cancer was to enter into a new-to-herself embodied sphere. To then find, somehow along the way, that she was living in suspension with MBC, was to enter yet another new-to-herself embodied sphere. MBC, as living⇔dying, was more nebulous than advancing illness; it was less defined, having fewer strict boundaries strewn across their lives and within each of their bodies. The discussion of boundary crossings shows that the women were navigating their lives with few reliable directions they could turn to in daily life. This discussion also shows how they were enduring through the engagement of horizons of hope and possibilities for generating a well-lived life. Transpositions is an entry point into stories that are getting closer to being ‘just big enough’ to keep hold of complexities that make up women’s embodied lives.

There were two sub-resonances of bodily transpositions. First, the women navigated daily life with few set waymarkers. Their actions often took the form of mediating turbulence around social belonging, sorting through unclear body signals, and untangling categories of medical status. Second, hope took on new forms for the women and living with MBC became a distinctive kind of endurance. They mediated small practices of hope that were nourishing daily steps in what it was to be living with MBC for months, while they actively created pathways for living by drawing upon medical advancements in therapeutics.

Along with the resonance of temporal pulses (Chapter 5), bodily transpositions offer some resolution to my research question for this project, disclosing how a multitude of uncertainties and ill-fitting stories of MBC manifest in women’s day-to-day lives. Using bodily transpositions disclose how women with suspended forms of MBC become living⇔dying subjects.

In the next chapter, I conclude the dissertation by discussing theoretical, methodological, and empirical contributions of this project. I include in that chapter possible clinical implications and directions for future research.

Chapter 7: Reflections

> This is a country both narrow and vast, where geography bends at the edges and landmarks vanish like Cheshire cats. “Oh, we don’t use that drug anymore,” a doctor will say, five minutes after the drug was invented. So, you have to become your own cartographer, make your own way.
>
> — Katherine Russell Rich (2010), on nine years with MBC

Specific to women’s daily lives with MBC today, metastatic breast cancer (MBC) is an understudied life-limiting illness. From my review of the literature and MBC in the community, there are indications that MBC is changing from being defined primarily by imminent death, to filled with possibilities of living⇔dying. Yet, there is still debate about what MBC may or may not be becoming. There are questions about what it is like for women to live with forms of MBC, whether for months, years, or even decades. What is clear, is that for those of us in healthcare and cancer support, these is a need for revitalized ways to speak about MBC today. The theoretical framework for this project provides a way to do that.

For this project, I had conversations with women who had lived relatively well with MBC for at least two years and who lived in small communities where travelling for medical treatment can be a regular part of life. I found that characterizing their lives, were *temporal pulses*, time that was structurally unmoored, and *bodily transpositions*, boundary crossings of living multiple embodied positions at one time. The women’s stories had aspects of what is already known about advanced cancer and life-limiting illness, as well as new ones with degrees of difference that could be deceptively subtle. In this final chapter, I discuss key theoretical, methodological, and empirical contributions of this research, as well as future directions for both practice and research.

Theoretical Contributions

Working within a 'relational materialist' approach was not a straightforward task. However, it did lead to a generative, whilst practical inquiry. My work makes three key theoretical contributions. First, in this project, the relational material subject is a living⇔dying subject, a framing that speaks to the indeterminacy of the lives of women who are suspended within a life-limiting illness. Second, applying a relational materialist approach introduces a different vocabulary to talk about MBC, one which can capture the complex dimensions of living⇔dying with cancer today. Third, by thinking in relational terms about how bodies traverse illness and death, using the term 'transpositions' becomes a useful framing for understanding how women live and die with MBC.

Relational Material Subject as Living⇔Dying Subject

A distinctive element of my project is that I show how the relational material subject is a living⇔dying subject, via women living with MBC in suspension. In the literature, regardless of their intellectual genealogy, most material feminists deal with either a living subject *or* a dying subject. In contrast, I am interested in the space where subjects are *both* living and dying. Sensitivity to Braidotti's feminist arguments around tempering critique by being compassionate and creative in the analysis permitted me to disclose nuances of the living⇔dying subject for these women living with MBC. The living⇔dying subject works well to think about the women's stories of their life since the time it became clear that MBC was a matter of endurance rather than end-of-life.

As discussed in Chapter 3, the living⇔dying subject offers practitioners and other readers a way to think about the ambiguous states of being that women with suspended MBC have been living in. Mine is a theoretically-informed practitioner inquiry, a key factor of which is how the living⇔dying subject is an invitation to consider uncertainties of who women with MBC may be becoming, as their lives defy the dominant scripts demarking the path MBC usually takes in individual lives. The living⇔dying subject is a woman-centred alternative to conventionally operationalized categories of health, disease, illness, healthcare, or other inflexible categories that may limit our work in providing care for women with MBC. The living⇔dying subject also fits a palliative approach in that it considers the messiness of living with life-limits and is open to opportunities for living life relative to what bodies with MBC have to offer.

A Different Vocabulary for MBC

For this project, a relational materialist approach worked well to provide a different way to talk about MBC, shifting into the Life element of life-limiting illness while retaining a practical engagement with the grittiness of daily life. The dissertation's breadth is an exercise in critical thinking, evaluating how MBC is talked about, including by the women themselves and the healthcare providers they encounter. I put forward a different vocabulary so that the talk can be clearer about the fluctuations of this illness that women may live with today. Vocabulary that supports women by increasing understanding of daily life with suspended forms of MBC. Thinking about how we talk about MBC is in the spirit of palliative social work literature advocating for a focus on strengths and growth, rather than on dysfunction and deficits. This approach asks those of us in healthcare to consider the frames we look through in practice and to move away from a pathological or disease-focused lens. An example of this strengths perspective practice is the work of Cadell and colleagues, a Canadian leader in palliative social work (e.g., Grant & Cadell, 2009; Cadell, Shermak, & Johnston, 2011)

If taken as a whole, the lexicon I shared in Chapter 2 works as a set of entry points for thinking about generative ways to discuss MBC. 'Suspension' works as a purposefully provisional way to describe MBC that creates space for engaging forms of MBC that have not yet been encountered; that is, they are, in some way, a surprise. 'Metastatic' works as thinking anew on movement within suspended MBC, as well as how movement is at play variously in the different women's lives. 'Life-limiting illness' works as an encounter with the thicket of limits that is the day-to-day of living with suspended MBC. Carefully considering language is worthwhile for practitioners, because communication is vital to the work across diverse practices. Part of that equation is having an understanding of the impact of words. For practitioners, by understanding the body as relational, there is room for more sensitivity to the effects of the words used to describe MBC, inclusive of the material consequences.

Transpositions as a Framing of MBC

The notion of 'transpositions' captures a lot of what I had been thinking about in this project. Transpositions is a means to think beyond binaries, categorizations, and other static constructs that may not be up to the task of today's uncertainties and complexities of

MBC. For example, I developed a more nuanced understanding of the needs of women living with MBC through a reconsideration of how biomedical classifications such as palliative care patient, cancer care patient, or person with a chronic illness apply to women with MBC. By thinking about transpositions and how women embody a liminal living⇔dying subject, a practitioner can engage in ongoing negotiations of who the women may be, today and over time.

Transpositions speak to how medical technologies are shaping the embodied presence of MBC, intentionally or otherwise. Transpositions is a framing that provides a means to talk about the shifting boundaries of what separates living from dying, and vice versa. While talk along such boundaries occurs informally in healthcare practice sites, perhaps most often among those who work closely with clients deemed palliative and their families, what transpositions offer is a way to work towards new common languages and to invite renewed discussion on what constitutes best practice.

It was refreshingly jarring, and indeed practical, to not think in terms of transitions or phases when it comes to life-limiting illness. 'Transitions' is the normative biomedical language within end of life care, including the literature, and serves many purposes to speak of the client's changing needs as they move through illness trajectories towards the end of life. However, just as a palliative approach expands on palliative care as a mode of practice, thus better addressing nuances of life with illness, transpositions offer a renewed emphasis on embedded and embodied needs of those living and dying, including ones specific mortality and pain. Transpositions in its expansiveness positioned me as a practitioner on a more equal footing with the expressions of suspended MBC. This expansiveness also allowed me to stay with the state of uncertainty and unexpectedness of an advanced breast cancer. Transpositions can support dynamic pathways for healing as guided by those who need them.

Methodological Contributions

I designed my inquiry to explore how women are produced as living⇔dying subjects. There are three key methodological contributions of my project. First, by reframing my MBC inquiry through a critical, relational materialist approach, I was able to address the lack of literature on women living with MBC, including on living longer, and to undertake generative research attuned to women's stories, beyond conventional biomedical framings of MBC. Second, project findings speak to what can be learned from how women with non-conventional forms of breast cancer self-selected for this project. Third, staying close to the women's words while sustaining a politically-informed ethics for this project, led to a diversified, yet practical, engagement with their stories.

Reframing MBC Inquiry

My project addresses the lack of research on living with MBC, with noted gaps in both the literature on the divergent trajectories of illness and women living in smaller communities, outside central nodes of healthcare provision. My project also addresses the lack of different approaches for researching and understanding MBC in the literature, where few studies contest or expand on conventional biomedical framings of illness. In this way, my research connects with conversations about better meeting the needs of those who have a life-limiting illness, directly addressing dying and other needs specific to those illnesses. An example from the British Columbian Coast is that of Stajduhar and colleagues, who I touched on in Chapter 2 (also see Stajduhar, 2011).

I believe my project was informative and timely to explore the lives of women with MBC, by going deeper into the women's accounts of the way MBC as an illness fluctuates. My research in this dissertation is part of a newer body of literature that explores life-limiting illnesses where people are living longer because of advances in biotechnologies. For example, there is the work of Thorne and colleagues on chronic cancer, which comes out of western British Columbia; please see Chapters 1 and 2. With the focus on living⇔dying, my research can also be compared with the life-limiting illness or serious illness literature that includes the liminal and the in-between. This literature is diverse, given the different theoretical approaches and life-limiting illnesses of interest. An example from the British Columbian Coast comes from Sheilds and colleagues who applied a social constructionist perspective to explore stories of three life-threatening illnesses, including cancer, and how they were restoried over time (e.g., Bruce et al., 2014; Sheilds et al., 2015).

In terms of reframing MBC, a seemingly small part of this study which turned out to be significant, was how I designed an interview question specifically to ask each woman how she would define her illness (see the closing question in Appendix J). My findings speak to how "knowledge that is too often missing and is often desperately needed is at the intersection between things and people, between experiences … and bodies" (Tuana, 2008, p. 189). My research fits with literature contesting normative discussions of breast cancer, including survivorship (for examples, see Chapter 2). Relational materialist theorizing worked well with project data to create space for women's embodied stories. My project does address the invisibility of women's lives in smaller communities with any kind of MBC and of women's lives with ambiguous forms of MBC.

In addressing missing knowledge, what worked particularly well was having an enlarged sense of the women's stories open to complexities, where, vis-à-vis Haraway (2016a) I worked in my writing to make room for stories that were a good fit, "just big enough" (p. 101). I thought relationally about what stories of MBC *could* look like. This notion of stories permitted me to design a project infused with an ethical concern for embodiment — for women's needs that were *of* the body yet, exceeded it, and for situatedness — for women's relational fit within their lived context. My project is one possible variation of a project of 'just big enough stories': a community-based practitioner-inquiry and a feminist approach accounting for one group of women who have a life-limiting illness where dying is extensively mediated by contemporary technologies. Ideally, my project will lead others to research living with MBC and to consider what their own projects of 'just big enough stories' could be.

Women Self-selecting for this Project

Most of the women who contacted me for project participation, including all who would become participants, self-selected for the project because of how it fits with their health or goals for a life fully lived. This self-selection led me to think about who were the women who did not contact me, and whose stories were not part of my dissertation work? Outside of those who would not choose to participate in research at all, could these women be those whose lives were simply too intense, those who could not fit the project into their lives and/or those whose management of MBC was not so learning-focused? My project addresses a significant gap in knowledge about women's embodied lives with suspended MBC. However, in thinking about the findings, despite a meticulous effort in recruitment to be far-ranging, my project does not address the breadth of the women who are living in smaller communities and healthcare categorization gaps; this is an area of future research, one where a different research design or approach could potentially yield more knowledge.

In this project, the design brought forward a distinct group of women. While there were marked differences in their backgrounds and their illness experiences, in their own particular way, each was highly motivated and committed to learning. This group of women, in turn, revealed two things: what hidden stories look like and what social isolation compounded by small communities, *as well as* illness trajectory, might mean. Interestingly the hidden stories of the women that my project did not include are also mostly absent in the stories shared by the women who came forward. Most of the women in this project had no contact with other women who had MBC, suspended or otherwise. Moreover, the women most often did not know about other women with MBC who lived geographically close to them. There is a degree of isolation between women with MBC, whether in physical communities or in social media ones where women may never meet face-to-face. One reason for this is how the breast cancer movement organizes women, including the talk about women with MBC. I shared literature in Chapter 2 that speaks to how women with MBC are excluded and/or marginalized in spaces open to breast cancer survivors. There were women in my research who had dropped out of local support groups because they found that they were the only woman there with an advanced form of breast cancer, and they did not fit with women who had early-stage breast cancers. In this project, compounding breast cancer-specific isolation was how the women felt strongly that few people could relate to what they were living with day-to-day. Social isolation is a significant area for further research, mainly because it appears that addressing isolation is a tricky, yet key, factor in navigating suspended MBC and living well with it. Concerning hidden stories, I am also struck by how many women who contacted me had statistically rare types of breast cancer, whether MBC or not, and how they were in great need of supports. More research is needed into these women's needs and into how their cancers are talked about across diverse social spaces.

Staying Close to the Women's Words, while Following a Politically-informed Ethics

I found applying a feminist relational materialist approach in empirical inquiry is to be committed to a politically-informed ethics both in the design and carrying out the research project. Ethics is a strong point of such an approach. There is an accompanying need to mediate tensions that come from how having a politically-informed ethics entails doing things a certain way. An ongoing tension in my project was resisting being an expert reporting on the lives of the women with MBC while working to be a relational materialist-informed practitioner and researcher. Another tension was retaining the balance of acting on a politically-informed ethics, while holding onto the women's words throughout the writing, editing, and refining of the dissertation. My commitment to a politically-informed ethics meant that I kept going deeper into the women's accounts rather than merely presenting an inventory of a set of women's experiences. This deeper engagement meant I was able to discuss diverse facets of living⇔dying that were part of women's day-to-day lives.

One of the project elements that helped me to stay with women's words was the feminist post qualitative writing style. Most useful was the goal of tentativeness in writing. I did not so much work towards absolute conclusions or facts, instead statements that engaged MBC as concurrently known and unknown, the messiness of living⇔dying. I was able to blend and temper my ethical commitment while working with data from interviews. Being tentative was often like the steadiness of bricklaying, with one small measured action after another. Through this writing style, I could work with words as living elements of 'just big enough stories.'

Empirical Contributions

To select empirical contributions, I considered facets of MBC as a "livable cancer" to borrow the words of one of the women in this study. There are three key empirical contributions of my work. First, the richness in the collected project material allowed for various complexities of, and uncertainties about, living⇔dying with MBC to come through in the women's stories. Second, the women held an MBC-specific workload, focused on finding out how to live with suspended forms of MBC, that shaped what their daily life is and what it could be. Third, the women were experts of all things while living⇔dying with MBC, because of the urgency and intensity of what it was for them to be suspended within the life-limiting illness known as MBC.

The Richness of Project Material

The empirical material of this project was rich enough that I could have read it in many different ways, even within the theoretical framework I applied. Because the material was rich (as per research design), I was able to more clearly convey what stories the women wanted to tell. Part of the strength of feminist post qualitative analysis is the ability to provide a prismatic reading of 'data' so that the complicatedness of the women's stories came through. While biomedical narratives go in one direction, the women's stories in this project suggest more "surprising new and old connections" (Haraway, 2016a, p. 101) to be found. One poignant example is how my project raises questions around age and stage of life: What is it to live with a suspended MBC as a mother of young children, or as a new retiree, or as a late-in-life senior?

Given the richness of the data, I have been able to show that there are women in smaller communities on Vancouver Island that have been affected by unconventional forms of MBC. These women are not only in need of improved supports, they also have rich stories to share that can inform provision of those supports. Each of the women in the project had specific things they wanted others to know and had particular hopes of supporting other women with MBC. The richness of data arose from the women in how they shared considerable detail, often intimate in nature. This richness of data was also the case with loved ones included in the cluster interviews, where I commonly found myself amidst an array of intense feelings. The women and their loved ones discussed their reflections, thoughts, and emotions about living⇔dying with MBC, which they rarely shared with others. The stories of agony, bewilderment, and resentment that I bore witness to, provided texture to the 'big enough stories.' These disclosed how the specifics of their lives emerged as key in what makes up living⇔dying with MBC, for example fresh and long-guarded hurt. The richness of material shared by project participants far exceeded project goals and added a more extensive understanding of whom a ‘woman with MBC’ might be and what exactly her daily life might entail.

Women are Living with an Amorphous Workload

Part of the richness of the data was that it disclosed the elements of the ever-changing workload of MBC as it flows in and out of apparent suspension, which in turn showed that the workload of ongoing MBC differed from more imminently life-threatening forms of MBC. This was a comparison made through consideration of the MBC literature and the accounts of the women in this project of their early days with MBC. The women’s stories provide a sense of the litany of tasks involved in having not only MBC, but also engaging living one’s life while living with an ongoing MBC. This workload the women were drawn into, involved navigating information about MBC from the beginning of the diagnosis process. While there might be ups and downs in the level of activity comprising the MBC workload, the women were continuously living with the work that living⇔dying with MBC generated. Because of the individualized way that the disease acts in each body, the shape of the workload varied. This amorphous workload informed the way the women needed to organize their time and to recognize shifts in the disease process in an attempt to provide direction for care.

My work in this project highlights some of the aspects of the women’s lives that feed into this amorphous workload for women living long-term with MBC. The types of information that the women in this project gathered and processed included insights into: breast cancer type needs, available resources, scientific advancements in medical technologies for advanced breast cancer, and other types of resources that women can draw on. Throughout both empirical resonances, the women indicated to what extent they had to take on the workload handed to them upon diagnosis and then how this all changed as their illness became one of living⇔dying. Finding their way into the maintenance of metastatic breast cancer was a convoluted learning process. There were various types of changes that would affect the workload of MBC. One of the most significant changes was that as women became more medically stable, they needed to take more control of their healthcare, regardless of whether or not they wanted to. There tended to be a shift in their healthcare management from primarily having to follow hard-and-fast 'requirements' set out by practitioners (who were adhering to healthcare policy, including cancer control programs) toward navigating 'suggestions' that did not conform to one perspective on disease management. Seeking out and then mapping these resources across their positioning in their small communities came with various costs and restrictions that, in turn, shaped the workload the women took on and carried with them. The layers of workload and maintenance of MBC that the women mediated over time suggest the need for more research into what living with MBC as a life-limiting illness entails and if this substantial, amorphous workload can be alleviated in some way. As part of the navigation of information about MBC that constitutes this workload, it might also be useful to develop and point toward resources that women could use to sustain living with, rather than dying from, MBC.

Women with Suspended MBC as Experts in all Things

Today is an information age where one has to be an expert on all things and your own life. One thing that stood out in my project was that to be living with an unexpected, unpredictable form of MBC meant that being such an expert took on a particular magnitude. Not only did the women have expertise about living with MBC as a life-limiting illness, but they also had expertise about living with a newer presentation of the disease that was still not well known in the greater social sphere. The women in this project actively navigated information coming from within the medical system and other wellness option providers. Over time, each of the women's decision-making process became increasingly sophisticated, particularly as medical information tended to become sparser and less conclusive. For example, the women came to resist, or outright reject, tethering themselves to specific pieces of medical information that could at times be imprecise or could arrive erratically, including tumour markers as health status indicators. The women also became adept at mediating conflicting information from the social sphere. For example, social media provided tips for living well and long with MBC, some of which might have been useful and some were not. In these ways, the women in this project became *curators*, in addition to being navigators, of information. These project findings add to a vast body of healthcare literature on the role of information in the lives of people with cancer, including what is commonly referred to as *information needs* and *information seeking*.

This project draws attention to how important it is to acknowledge that women who live with MBC have expertise which perhaps conventionally-known experts in the field do not. The women in this project faced extra pressure from being an expert in their lives because, in their communities, it was uncommon that there were experts in ongoing forms of MBC. Pressure also took the form of how it was common that women received fragments of viable information, that they, in turn, would have to figure out how to connect with their growing expertise on MBC. My project shows the complexity of the expertise women living⇔dying with MBC carry, as well as the complexities that come with having such knowledge. Project findings disclose a need for healthcare practitioners to be more aware of how women have MBC expertise and that they could use assistance managing the responsibility of expertise while trying to live well with MBC. Further, research into how women's expertise could be used for more than themselves would be valuable, in that it could provide more detail about what it is for women with MBC to be an expert not only in MBC but also in living⇔dying today.

Potential Clinical Implications and Future Research Directions

While clinical implications are not a focus of my project, there are numerous indications of how women's stories could offer further insights into healthcare provision. I note four of these here. First, the women in this project clearly benefited from encounters with practitioners who addressed them in highly contextual ways, not solely within biomedical framings of MBC. Second, there is value for practitioners to evaluate how they speak of MBC, resisting static, or seemingly out-of-date phrases, and to consider the material consequences for patients and families of how MBC is discussed. Third, the women in this project appreciated when their expertise on MBC and/or living⇔dying was recognized by practitioners, as well as how they could use support. Finally, alongside using revitalized ways to talk about MBC, there is a need to reimagine what generative living or living well with MBC could be, starting by asking women about their own goals and what wellness is to them. While I expected some of these points about clinical practice to emerge, some were surprising and were well beyond any thought I had before undertaking the research.

For future theoretical directions, my project indicates a need for more relational material analyses of MBC and other metastatic cancers to see what is revealed in terms of how living⇔dying subjects find ways to live life in embodied and material ways. Methodologically, given the changing status of MBC, it would be beneficial for post qualitative methodologies to be used more as part of MBC research. These offer alternative understandings of how MBC can be part of women's lives beyond biomedical renditions so that women can act in informed ways on their treatment and wellness. Empirically, there is a need to research how stage-of-life and ageing affects how to live with a suspended MBC.

Additionally, there are at least two other future research projects that I think arise directly out of my research project. First, designing a project that would purposefully seek out the hidden stories, mentioned earlier in this chapter, would be useful to provide a range of cancer stories that could challenge the genre of survivorship across various types of cancer. The project would need to have a big enough recruitment area to account for a presumed small number of these women in any one region. For example, focusing on the needs of those province-wide in rural British Columbia. As with suspended MBC, providing a forum for these women's stories and offering alternative understandings of their breast cancers could improve the lives of those impacted by MBC. Second, designing a post qualitative project to conduct comparative work on other illnesses, where people live in suspended states of living⇔dying, could further understanding about the materiality of disease management and people's embodied needs. MBC is part of a particular group of life-limiting illnesses that are dominated by biomedical framings. Such illnesses include, chronic obstructive pulmonary disease (COPD) and HIV. Comparative work across these types of illnesses where people are living longer under medical care provision, across varying geographical regions could have much to offer to the literature.

Conclusion

Building on the dissertation work, in this chapter, I focused on a discussion of project contributions: theoretically, methodologically, and empirically. First, I discussed the theoretical contributions of the relational material subject as a living⇔dying subject, a different vocabulary for MBC, and transpositions as a framing of MBC. Second, I discussed the methodological contributions of reframing MBC inquiry, reflecting on women self-selecting for this project, and staying close to the women's words, while following a politically-informed ethics. Third, I discussed the empirical contributions of the richness of project material, women with suspended MBC as experts in all things, and women as living with an amorphous workload. In closing, I discussed some potential clinical implications if the insights from this project were brought into clinical practice. I also noted some possible future research directions — theoretically, methodologically, and empirically.

The breadth of this dissertation research shows how women with MBC are produced as subjects who are living⇔dying. The analysis discloses new understandings of daily life with a life-limiting illness in several unexpected ways. Project findings offer much-needed insights on an illness that can be occluded by the long pink shadow of corporatized breast cancer and by the gravity of its long-standing association with imminent death, as well as its more recent association with chronicity. As discussed by the women in this project, suspended forms of MBC are a matter of navigating a paradoxical terrain of opportunities for Living amongst uncertainties and complexities emerging out of living longer, and longer still. A strength of this dissertation is that it is a practitioner's exercise of inhabiting questions on how to have a lens for healthcare practice attuned to the ways MBC presents today and how to speak of MBC in ways that resonate for those living with MBC. It is research that provides empirical evidence for those who are invested in awareness and support of women's needs to *live* with forms of MBC.

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Appendix A

An Exploration of Why I Have Taken Up This Research Topic

The following is an example of a note: I made this detailed note to assess what, beyond the literature might be compelling me to take on this project.

My awareness of advanced breast cancer originated in the grassroots culture of West Coast Canadian breast cancer advocacy during the late 1990s and early 2000s. This was a time of women-oriented rallies for raising awareness of breast cancer, which was a marginalized cancer at the time; of a growing community need for a BC Cancer Agency stand-alone site on Vancouver Island and of the rise of breast cancer dragon boating culture, first out of Vancouver then Nanoose Bay on Vancouver Island, before then becoming a global movement. During this time I was based out of Central Vancouver Island, including Qualicum Beach and Nanaimo. These were social contexts where there were very few direct conversations on metastatic breast cancer, but in breast cancer circles conversations on women dying from breast cancer were common.

I realize now that it was within breast cancer dragon boating circles, where I gained considerable insight into mortality and breast cancer. There are the public rituals of remembrance that the public is a party to, such as the ‘carnation toss’ ceremony that is part of dragon boat festivals. However, there are far more mortality-related experiences and informal rituals within the sport itself. There were the absences. Women would leave the sport to deal with a recurrence. Of those who did not return to paddling, some had debilitating chronic ailments, and some passed away. There were the occasional disappearances. Some women would leave then not be seen or heard from again. Leaving behind rumours that she died. There were also a myriad of team and personal rituals amongst paddlers to mark the loss of someone they knew who had had breast cancer. Over time, it was from within breast cancer dragon boating circles that I started to wonder whether: women's lives with advanced breast cancer might be changing, and people might be talking more about late-stage breast cancers, not just early-stages, both in breast cancer circles and in general society.

From that time period and extending into more years of advocacy, I have my observations about how women die with breast cancer and how many women are dying of breast cancer. I realized that frequency of death is important because one of the enduring threads that constitute the 'fight' for breast cancer awareness is supporting the search for a breast cancer cure. I have a particular embedded orientation on day-to-day life with breast cancer as a life-limiting illness and an awareness of shifts in its status as a life-limiting illness over many years.

I am aware that my doctoral project research interest had been incubated in small communities on central Vancouver Island yet came to fruition because of a confluence of events with much wider roots. In the late 2000s at the crowded intersection of my roles as an occasional community-based breast cancer advocate, healthcare social work clinician in community care employment, family caregiver for a parent and a close friend with metastatic breast cancer, and committed palliative approach proponent, I was inundated with growing evidence that perhaps metastatic breast cancer was not the disease we in breast cancer culture once knew; the disease that had been strictly understood as a "killer." The picture was not terribly clear, but MBC was not quite the looming signifier of imminent death that it once was, and it seemed shifting medical technologies played a role in this.

Further, I discovered that my observations were in line with those of fellow healthcare colleagues and breast cancer advocates. I became increasingly curious about the lives of women with MBC who had thought they had an end-stage disease, but now they were still living many months and even years later. I was curious most of all in the lives of women who did not benefit from living in large urban communities with a range of cancer supports in both healthcare and in non-profit circles. In non-urban communities, what were women's embodied accounts about an MBC that was unexpectedly ongoing and what did these stories have to contribute to understanding the support needs of these women? My awareness of this shifting reality led me to research contemporary discussions on MBC as a life-limiting illness, to get a better understanding of what might or might not be happening with women's lives in the life-limiting illness settings that I was a part of.

In reviewing what compels me to do this project, I also became aware of why I have been so adamant in critiquing women's lives with MBC rather than reporting on their experiences. From being within breast cancer communities for as long as I have, I have grown skeptical of survivorship because of the ways normative narratives omit and occlude the difficult realities of living with cancer. My first and foremost commitment is to the women who have breast cancer and to their stories. Any research project and its outcomes will have a degree of separation from the raw vitality and grit of women's lives and what they have to say about it all, yet I wanted to lessen the distance. I wanted to find approaches to research that would assist me in doing so. An intention that I need to acknowledge goes back as far as my association with grassroots breast cancer advocacy and working to make women's voices heard.

Appendix B

University of Victoria Research Ethics Board – Certificate of Approval

Human Research Ethics Board
Office of Research Services
Administrative Services Building
PO Box 1700 STN CSC
Victoria British Columbia V8W 2Y2 Canada
Tel 250-472-4545, Fax 250-721-8960
ethics@uvic.ca www.research.uvic.ca

University of Victoria

Certificate of Approval

PRINCIPAL INVESTIGATOR:	**Sheryl Shermak**	ETHICS PROTOCOL NUMBER Minimal Risk - Board members	14-223
UVic STATUS:	**Ph.D. Student**	ORIGINAL APPROVAL DATE:	03-Sep-14
UVic DEPARTMENT:	**INTD**	APPROVED ON:	03-Sep-14
SUPERVISOR:	**Dr. Kelli Stajduhar; Dr. Pamela Moss**	APPROVAL EXPIRY DATE:	02-Sep-15

PROJECT TITLE: **Embodying Living <=> Dying: Everyday Life with Metastatic Breast Cancer as a Chronic Illness**

RESEARCH TEAM MEMBER None

DECLARED PROJECT FUNDING: None

CONDITIONS OF APPROVAL

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

Modifications
To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.

Renewals
Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

Project Closures
When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.

Dr. Rachael Scarth
Associate Vice-President Research Operations

Certificate Issued On: 03-Sep-14

14-223 Shermak, Sheryl

University of Victoria
School of Nursing

Appendix C

Consent Form — Primary Participant Interviews

Participant Consent Form: Embodying Living ⇔Dying. Everyday Life with Metastatic Breast Cancer as a Chronic Illness

You are invited to participate in a study entitled Embodying Living ⇔ Dying: Everyday Life with Metastatic Breast Cancer as Chronic Illness that is being conducted by myself, Sheryl Shermak. I am an interdisciplinary doctoral student in the departments of Nursing and Human and Social Development at the University of Victoria.

You may contact me by calling [redacted]

As a graduate student, I am required to conduct research as part of the requirements for a graduate degree in interdisciplinary studies. The research study is being conducted under the supervision of both Dr. Kelli Stajduhar and Dr. Pamela Moss. You may contact my Dr. Stajduhar at [redacted] or Dr. Moss at [redacted].

Purpose and Objectives
The purpose of this research project is to provide insights into the experience of everyday life with metastatic breast cancer as a chronic illness. This is inquiry into the emerging social phenomenon of living with a serious, life-threatening illness as a chronic not acute health condition.

The guiding question for this study is: Living with advanced breast cancer over an extended period of time how do women become a particular kind of individual with a suspended (chronic) form of serious illness? The research aims to reveal various dynamics that contribute to shaping these women's subjectivities (identities) as individuals, who are living with metastatic breast cancer as a chronic illness.

Importance of this Research
Research of this type is important because it will contribute to healthcare conversations on the complexities and the uncertainties of living with a serious illness well past prognosis and into the realities of chronic illness. Chronic advanced breast cancer is an increasingly common example of this phenomenon but is not well-understood by both healthcare professionals and the general public. It is hoped that insights from this study will contribute to improving supportive care and communities for individuals impacted by serious illness.

Participants Selection
You are being invited to participate in this study because you have the experience of living with advanced breast cancer over a prolonged period of time and you are currently living with breast

cancer as a chronic not acute illness. I am interested in hearing stories about your everyday life with chronic advanced cancer.

What is involved

If you consent to voluntarily participate in this research, your participation will include conversations about your experiences of living with chronic advanced breast cancer. Specifically:

[Please note: The below are working guidelines of this study and if you participate in this study every effort will be made to accommodate any changes in your life circumstances or health.]

1) Two face-to-face interviews at a time and location of your choosing, for example your home. Ideally these two interviews will happen about two weeks apart. Each interview will be approximately one hour in length. As needed, I will use questions from an interview guide to facilitate conversation. For the ~~sole~~ purpose of analyzing the information you share, digital audio recording and written notes will be taken.

Further written transcriptions of audio-recordings will be made.

Optional — for the purpose of providing a comprehensive picture of your experience: During the first interview, you will be invited to share resources that have informed how you understand and/or navigate your illness experience (for example: newspaper clippings, personal mementos etc.). You may share such objects or artifacts at that first meeting or the next. The purpose of collecting artifacts is to consider key material data that augments your stories, providing a more comprehensive understanding of your everyday life. These will be returned to you promptly. If you share objects, I will ask you whether I may take photographs of these objects for the purpose of analyzing data and/or for presenting study findings to others. If you agree to either or both, I will ask you to make a brief note of this at the bottom of this form, including your signature and the date. Between the first and second interviews you will also be invited to compose a brief 1–3 page account of everyday life with your illness. A document that you can then share at the second interview.

A further option, at the start of the first interview I will ask whether I may share brief audio clips of your interviews during public presentations of the research study and findings. The purpose being to augment transcribed materials and help bring your experiences to life by having your stories told in your own voice. I would select particular clips and then vet them with you before they were shared publicly, any you did not want share would not be (I would do so during the follow-up telephone call). If you agree, I will ask you to sign at the bottom of this form. Your signature will mean that I may contact you to review particular audio clips of interest. I would not use any clips without your expressed consent. Further, if consent is granted after review I would ask for written consent of particular clips in the form of a brief written correspondence (for example, an email).

2) One follow-up telephone conversation that will be about 20 minutes. This will provide an opportunity for discussion of further insights and comments. Further, you will be invited to engage in discussion on preliminary findings of the study if you wish. This phone call will occur at a mutually convenient time, ideally within three weeks of the final face-to-face interview.

I anticipate your total time commitment for the study would be spread over a two-month period and be about 4–5 hours in total.

Inconvenience

Participation in this study may cause some inconvenience to you, including time allowance for interviews. To help diffuse this potential inconvenience, interview time and location will be at your discretion. Further, every effort will be made to accommodate you if there are unforeseen circumstances that impact your participation in this study and you still want to continue to participate.

Risks

There are ~~no~~ few known or anticipated risks to you by participating in this research. ~~However,~~ I acknowledge that the experience of discussing and reflecting on your illness may not always be a comfortable one. In case of emotional discomfort or distress, time and support will be provided to address these concerns. Further, I acknowledge that part of your illness experience may be fatigue and stress. Participation in this study, including scheduling of interviews, will be guided by your wishes and needs.

Benefits

In general, there is limited research on living with the new social phenomenon of chronic advanced breast cancer. This study will illuminate realities of everyday life with this new chronic illness and how one becomes a particular kind of individual in society who has an ambiguous form of serious illness. The potential benefits of your participation in this research include the opportunity to openly reflect upon and discuss your experiences of illness in the unique context of health inquiry, a context where the researcher has both interest in and experience with serious illness. Health care providers may find this research helpful to their practice as it will provide insight about a client group that by their presence, challenges conventional understandings of serious illness and also raises questions as to how to best support them.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any explanation or consequences. If you do withdraw from the study, you will be asked whether you would like the data you have provided be included or removed from the study (for example, data from interviews). Please know that if analysis has already occurred, there may be difficulties in removing the data. However, all reasonable means will be taken to respect your choice.

On-going Consent

To ensure that you continue to grant your consent to participate in this research, I will both make reference to this consent form and verbally inquire if you continue to consent at the beginning of each interview and the follow-up telephone conversation.

Anonymity and Confidentiality

Please note: the context of your community being small may pose limits on efforts to protect your confidentiality. Efforts will be made to protect your confidentiality and the confidentiality of the data. To help ensure anonymity all personal identifiers will be removed from transcripts. For purposes of identification, numeric codes will be used on all documents, digital recordings and transcriptions. With published materials, fictional names will be used.

In terms of data storage, all physical data with be kept in a located cabinet within the researcher's home office and electronic material will be kept on a password encrypted computer.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in two forums: academic and general public. Within academia, this will take the form of published academic articles and presentations to interested groups, such as at a psychosocial oncology seminar. Further, research will be part of my dissertation document which will be available online through UVicSpace (part of the graduation requirement). With the general public, there will be educational lay literature developed, discussion in local media forums and public presentations. Final study findings will also be shared with research participants, for those who wish to have them.

Disposal of Data

Digital audio recordings of interviews will be erased after data analysis is complete. An exception, being if you grant permission to use audio clips from interviews as part of public presentations. In which case audio recordings will be erased within seven years. Paper copies of interview transcripts will be destroyed after seven years by document shredding. If you have provided any material objects for consideration these will be returned to you during the second interview if possible or if provided during the second interview then within two weeks of the exchange. If you have provided any written brief illness accounts these will be destroyed or returned to you after data analysis is complete.

Contacts

You may contact myself at [redacted]

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

Interview 1:

Name of Participant	*Signature*	*Date*

Interview 2: (Please note: if you are submitting a written account of your illness, consent is implied by your signature here.)

Name of Participant	*Signature*	*Date*

CONSENT TO CONTACT — REVIEW OF AUDIO CLIPS (FOR POSSIBLE USE IN PUBLIC PRESENTATIONS)

Name of Participant	*Signature*	*Date*

A copy of this consent will be left with you, and a copy will be taken by the researcher.

University
of Victoria
School of Nursing

Appendix D

Consent Form — Cluster Interviews: Professionals

Participant Consent Form: Embodying Living ⇔Dying. Everyday Life with Metastatic Breast Cancer as a Chronic Illness

You are invited to participate in a study entitled Embodying Living ⇔ Dying: Everyday Life with Metastatic Breast Cancer as Chronic Illness that is being conducted by myself, Sheryl Shermak. I am an interdisciplinary doctoral student in the departments of Nursing and Human and Social Development at the University of Victoria.

You may contact me by calling [redacted]

As a graduate student, I am required to conduct research as part of the requirements for a graduate degree in interdisciplinary studies. The research study is being conducted under the supervision of both Dr. Kelli Stajduhar and Dr. Pamela Moss. You may contact my Dr. Stajduhar at [redacted] or Dr. Moss at [redacted].

Purpose and Objectives

The purpose of this research project is to provide insights into the experience of everyday life with metastatic breast cancer as a chronic illness. This is inquiry into the emerging social phenomenon of living with a serious, life-threatening illness as a chronic not acute health condition.

The guiding question for this study is: Living with advanced breast cancer over an extended period of time how do women become a particular kind of individual with a suspended (chronic) form of serious illness? The research aims to reveal various dynamics that contribute to shaping these women's subjectivities (identities) as individuals, who are living with metastatic breast cancer as a chronic illness.

Importance of this Research

Research of this type is important because it will contribute to healthcare conversations on the complexities and the uncertainties of living with a serious illness well past prognosis and into the realities of chronic illness. Chronic advanced breast cancer is an increasingly common example of this phenomenon but is not well-understood by both healthcare professionals and the general public. It is hoped that insights from this study will contribute to improving supportive care and communities for individuals impacted by serious illness.

Participants Selection

You are being invited to participate in this study because a woman living long-term with advanced breast cancer has identified you as a person with considerable knowledge about serious illness and advanced breast cancer. I am interested in hearing stories about your experiences with and knowledge on advanced cancer.

What is involved

If you consent to voluntarily participate in this research, your participation will include conversations about your knowledge of living with chronic advanced breast cancer. Specifically:

[Please note: The below are working guidelines of this study and if you participate in this study every effort will be made to accommodate any changes in your life circumstances.]

1) One face-to-face interview at a time and location of your choosing, for example your home or office. The interview will be approximately 30 minutes to 60 minutes in length. I will use questions from an interview guide to facilitate conversation. For the purpose of analyzing the information you share, digital audio recording and written notes will be taken.

Further written transcriptions of audio-recordings will be made.

Optional — for the purpose of providing a comprehensive picture of your experience and knowledge: During the interview, you will be invited to share resources that have informed how you understand the illness experience (for example: newspaper clippings, professional practice documents, etc.). If you share materials please remove or mask any material that may identify other individuals. The purpose of collecting artifacts is to consider key material data that augments the stories you would share, providing a more comprehensive understanding. These will be returned to you promptly. If you share objects, I will ask you whether I may take photographs of these objects for the purpose of analyzing data and/or for presenting study findings to others. If you agree to either or both, I will ask you to make a brief note of this at the bottom of this form, including your signature and the date.

I anticipate your total time commitment for the study would be no more than1 hour.

Inconvenience

Participation in this study may cause some inconvenience to you, including time allowance for interviews. To help diffuse this potential inconvenience, interview time and location will be at your discretion. Further, every effort will be made to accommodate you if there are unforeseen circumstances that impact your participation in this study and you still want to continue to participate.

Risks

There are few known or anticipated risks to you by participating in this research. I acknowledge that the experience of discussing and reflecting on illness experiences may not always be a comfortable one. In case of emotional discomfort or distress, time and support will be provided to address these concerns. Participation in this study, including scheduling of the interview, will be guided by your wishes and needs.

Benefits

In general, there is limited research on living with the new social phenomenon of chronic advanced breast cancer. This study will illuminate realities of everyday life with this new chronic illness and how one becomes a particular kind of individual in society who has an ambiguous form of serious illness. The potential benefits of your participation in this research include the opportunity to openly reflect upon and discuss your experiences of illness in the unique context of health inquiry, a context where the researcher has both interest in and experience with serious illness. In terms of professional practice, health care providers may find this research helpful to their practice as it will provide insight about a client group that by their presence, challenges conventional understandings of serious illness and also raises questions as to how to best support them.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any explanation or consequences. If you do withdraw from the study, you will be asked whether you would like the data you have provided be included or removed from the study (for example, interview data). Please know that if analysis has already occurred, there may be difficulties in removing the data. However, all reasonable means will be taken to respect your choice.

Anonymity and Confidentiality

Please note: the context of your community being small may pose limits on efforts to protect your confidentiality. In addition to those limits, you may be identifiable to the person who suggested you to be recruited in this study. Efforts will be made to protect your confidentiality and the confidentiality of the data. To help ensure anonymity all personal identifiers will be removed from transcripts. For purposes of identification, numeric codes will be used on all documents, digital recordings and transcriptions. With published materials, fictional names will be used.

In terms of data storage, all physical data with be kept in a located cabinet within the researcher's home office and electronic material will be kept on a password encrypted computer.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in two forums: academic and general public. Within academia, this will take the form of published academic articles and presentations to interested groups, such as at a psychosocial oncology seminar. Further, research will be part of my dissertation document which will be available online through UVicSpace (part of the graduation requirement). With the general public, there will be educational lay literature developed, discussion in local media forums and public presentations. Final study findings will also be shared with research participants, for those who wish to, to have them.

Disposal of Data

Digital audio recordings of interviews will be erased after data analysis is complete. An exception, being if you grant permission to use audio clips from interviews as part of public presentations. In which case audio recordings will be erased within seven years. Paper copies of interview transcripts will be destroyed after seven years by document shredding. If you have provided any material objects for consideration these will be returned to you during the second interview if possible or if provided during the second interview then within two weeks of the exchange. If you have provided any written brief illness accounts these will be destroyed or returned to you after data analysis is complete.

Contacts

You may contact myself at [redacted]

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

<u>Interview:</u>

Name of Participant	*Signature*	*Date*

A copy of this consent will be left with you, and a copy will be taken by the researcher.

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Appendix E

Consent Form — Cluster Interviews: Non-Professionals

Participant Consent Form: Embodying Living ⇔Dying. Everyday Life with Metastatic Breast Cancer as a Chronic Illness

You are invited to participate in a study entitled Embodying Living ⇔ Dying: Everyday Life with Metastatic Breast Cancer as Chronic Illness that is being conducted by myself, Sheryl Shermak. I am an interdisciplinary doctoral student in the departments of Nursing and Human and Social Development at the University of Victoria.

You may contact me by calling [redacted]

As a graduate student, I am required to conduct research as part of the requirements for a graduate degree in interdisciplinary studies. The research study is being conducted under the supervision of both Dr. Kelli Stajduhar and Dr. Pamela Moss. You may contact my Dr. Stajduhar at [redacted] or Dr. Moss at [redacted].

Purpose and Objectives

The purpose of this research project is to provide insights into the experience of everyday life with metastatic breast cancer as a chronic illness. This is inquiry into the emerging social phenomenon of living with a serious, life-threatening illness as a chronic not acute health condition.

The guiding question for this study is: Living with advanced breast cancer over an extended period of time how do women become a particular kind of individual with a suspended (chronic) form of serious illness? The research aims to reveal various dynamics that contribute to shaping these women's subjectivities (identities) as individuals, who are living with metastatic breast cancer as a chronic illness.

Importance of this Research

Research of this type is important because it will contribute to healthcare conversations on the complexities and the uncertainties of living with a serious illness well past prognosis and into the realities of chronic illness. Chronic advanced breast cancer is an increasingly common example of this phenomenon but is not well-understood by both healthcare professionals and the general public. It is hoped that insights from this study will contribute to improving supportive care and communities for individuals impacted by serious illness.

Participants Selection

You are being invited to participate in this study because you have been identified as a key support person by a woman living long-term with advanced breast cancer. I am interested in hearing stories about your experience with chronic advanced cancer.

What is involved

If you consent to voluntarily participate in this research, your participation will include conversations about your perspective on the experiences of living with chronic advanced breast cancer. Specifically:

[Please note: The below are working guidelines of this study and if you participate in this study every effort will be made to accommodate any changes in your life circumstances.]

1) One face-to-face interview at a time and location of your choosing, for example your home or office. The interview will be approximately one hour in length. As needed, I will use questions from an interview guide to facilitate conversation. For the purpose of analyzing the information you share, digital audio recording and written notes will be taken.

Further written transcriptions of audio-recordings will be made.

Optional — for the purpose of providing a comprehensive picture of your experience and knowledge: During the interview, you will be invited to share resources that have informed how you understand and/or navigate your illness experience (for example: newspaper clippings, personal mementos etc.). I would ask that if you share materials that you remove or mask any material that may identify other individuals. The purpose of collecting artifacts is to consider key material data that augments the stories you would share, providing a more comprehensive understanding of your stories. These will be returned to you promptly. If you share objects, I will ask you whether I may take photographs of these objects for the purpose of analyzing data and/or for presenting study findings to others. If you agree to either or both, I will ask you to make a brief note of this at the bottom of this form, including your signature and the date.

I anticipate your total time commitment for the study would be no more than 2 hours.

Inconvenience

Participation in this study may cause some inconvenience to you, including time allowance for interviews. To help diffuse this potential inconvenience, interview time and location will be at your discretion. Further, every effort will be made to accommodate you if there are unforeseen circumstances that impact your participation in this study and you still want to continue to participate.

Risks

There are few known or anticipated risks to you by participating in this research. I acknowledge that the experience of discussing and reflecting on your experiences with illness may not always be a comfortable one. In case of emotional discomfort or distress, time and support will be provided to address these concerns. Participation in this study, including scheduling of the interview, will be guided by your wishes and needs.

Benefits

In general, there is limited research on living with the new social phenomenon of chronic advanced breast cancer. This study will illuminate realities of everyday life with this new chronic illness and how one becomes a particular kind of individual in society who has an ambiguous form of serious illness. The potential benefits of your participation in this research include the opportunity to openly reflect upon and discuss your experiences of illness in the unique context of health inquiry, a context where the researcher has both interest in and experience with serious illness. Health care providers may find this research helpful to their practice as it will provide insight about a client group that by their presence, challenges conventional understandings of serious illness and also raises questions as to how to best support them.

Voluntary Participation
Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any explanation or consequences. If you do withdraw from the study, you will be asked whether you would like the data you have provided be included or removed from the study (for example, interview data). Please know that if analysis has already occurred, there may be difficulties in removing the data. However, all reasonable means will be taken to respect your choice.

Anonymity and Confidentiality
Please note: the context your community being small may pose limits on efforts to protect your confidentiality. In addition to those limits, you may be identifiable to the person who suggested you to be recruited in this study. Efforts will be made to protect your confidentiality and the confidentiality of the data. To help ensure anonymity all personal identifiers will be removed from transcripts. For purposes of identification, numeric codes will be used on all documents, digital recordings and transcriptions. With published materials, fictional names will be used.

In terms of data storage, all physical data with be kept in a located cabinet within the researcher's home office and electronic material will be kept on a password encrypted computer.

Dissemination of Results
It is anticipated that the results of this study will be shared with others in two forums: academic and general public. Within academia, this will take the form of published academic articles and presentations to interested groups, such as at a psychosocial oncology seminar. Further, research will be part of my dissertation document which will be available online through UVicSpace (part of the graduation requirement). With the general public, there will be educational lay literature developed, discussion in local media forums and public presentations. Final study findings will also be shared with research participants, for those who wish, to have them.

Disposal of Data
Digital audio recordings of interviews will be erased after data analysis is complete. An exception, being if you grant permission to use audio clips from interviews as part of public presentations. In which case audio recordings will be erased within seven years. Paper copies of interview transcripts will be destroyed after seven years by document shredding. If you have provided any material objects for consideration these will be returned to you during the second interview if possible or if provided during the second interview then within two weeks of the exchange. If you have provided any written brief illness accounts these will be destroyed or returned to you after data analysis is complete.

Contacts
You may contact myself at [redacted]

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

<u>Interview:</u>

______________________________	______________________________	______________
Name of Participant	*Signature*	*Date*

A copy of this consent will be left with you, and a copy will be taken by the researcher.

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Appendix F

Consent Form — Key Informant Interviews

Key Informant Consent Form: Embodying Living ⇔Dying.
Everyday Life with Metastatic Breast Cancer as a Chronic Illness

You are invited to participate in a study entitled Embodying Living ⇔ Dying: Everyday Life with Metastatic Breast Cancer as Chronic Illness that is being conducted by myself, Sheryl Shermak. I am an interdisciplinary doctoral student in the departments of Nursing and Human and Social Development at the University of Victoria.

You may contact me by calling [redacted]

As a graduate student, I am required to conduct research as part of the requirements for a graduate degree in interdisciplinary studies. The research study is being conducted under the supervision of both Dr. Kelli Stajduhar and Dr. Pamela Moss. You may contact my Dr. Stajduhar at [redacted] or Dr. Moss at [redacted].

Purpose and Objectives

The purpose of this research project is to provide insights into the experience of everyday life with metastatic breast cancer as a chronic illness. This is inquiry into the emerging social phenomenon of living with a serious, life-threatening illness as a chronic not acute health condition.

The guiding question for this study is: Living with advanced breast cancer over an extended period of time how do women become a particular kind of individual with a suspended (chronic) form of serious illness? The research aims to reveal various dynamics that contribute to shaping these women's subjectivities (identities) as individuals, who are living with metastatic breast cancer as a chronic illness.

Importance of this Research

Research of this type is important because it will contribute to healthcare conversations on the complexities and the uncertainties of living with a serious illness well past prognosis and into the realities of chronic illness. Chronic advanced breast cancer is an increasingly common example of this phenomenon but is not well-understood by both healthcare professionals and the general public. It is hoped that insights from this study will contribute to improving supportive care and communities for individuals impacted by serious illness.

Participants Selection

You are being invited to participate in this study because you are known be a practitioner with comprehensive knowledge on individuals living with serious illness, including advanced breast cancer. In particular, I am interested in hearing about your experience with and your perspective on chronic advanced breast cancer.

What is involved
If you consent to voluntarily participate in this research, your participation will involve a conversation about experiences of living with chronic advanced breast cancer. Specifically:

One face-to-face interview at a time and location of your choosing, for example your office. The interview will be approximately 30–60 minutes in length. I will use questions from an interview guide to facilitate conversation. For the purpose of analyzing the information you share, digital audio recording and written notes will be taken.

Further written transcriptions of audio-recordings will be made.

Optional — for the purpose of providing a comprehensive picture of living with chronic advanced cancer: During the interview, you will be invited to share resources that have informed your understanding of the illness experience (for example: newspaper clippings, website addresses, policy documents, or reference books). These will be returned to you promptly. If you decide to share resources, I will ask you to make a brief note of this at the bottom of this form, including your signature and the date.

I anticipate your total time commitment for the study would be no more than 1 hour and likely in the range of 30 minutes.

Inconvenience
Participation in this study may cause some inconvenience to you, including time allowance for interviews. To help diffuse this potential inconvenience, interview time and location will be at your discretion. Further, every effort will be made to accommodate you if there are unforeseen circumstances that impact your participation in this study and you still want to continue to participate.

Risks
There are few known or anticipated risks to you by participating in this research. I acknowledge that the experience of discussing and reflecting on serious illness may not always be a comfortable one. In case of emotional discomfort or distress, time and support will be provided to address these concerns. Participation in this study, including scheduling of the interview, will be guided by your wishes.

Benefits
In general, there is limited research on living with the new social phenomenon of chronic advanced breast cancer. This study will illuminate realities of everyday life with this new chronic illness and how one becomes a particular kind of individual in society who has an ambiguous form of serious illness. The potential benefits of your participation in this research include the opportunity to openly reflect upon and discuss your expertise on illness in the unique context of health inquiry, a context where the researcher has both interest in and experience with serious illness. Also your participation would add knowledge to health care practice. Health care providers may find this research helpful to their practice as it will provide insight about a client group that by their presence, challenges conventional understandings of serious illness and also raises questions as to how to best support them.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any explanation or consequences. If you do withdraw from the study, you will be asked whether you would like the data you have provided be included or removed from the study. Please know that if analysis has already occurred, there may be difficulties in removing the data. However, all reasonable means will be taken to respect your choice.

Anonymity and Confidentiality

Please note: if you are from a non-urban community, the context of your community being small may pose limits on efforts to protect your confidentiality.

Efforts will be made to protect your confidentiality and the confidentiality of the data. To help ensure anonymity all personal identifiers will be removed from transcripts. For purposes of identification, numeric codes will be used on all documents, digital recordings and transcriptions. With published materials, fictional names will be used.

In terms of data storage, all physical data with be kept in a located cabinet within the researcher's home office and electronic material will be kept on a password encrypted computer.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in two forums: academic and general public. Within academia, this will take the form of published academic articles and presentations to interested groups, such as at a psychosocial oncology seminar. Further, research will be part of my dissertation document which will be available online through UVicSpace (part of the graduation requirement). With the general public, there will be educational lay literature developed, discussion in local media forums and public presentations. Final study findings will also be shared with research participants, for those who wish, to have them.

Disposal of Data

Digital audio recordings of interviews will be erased after data analysis is complete. Paper copies of interview transcripts will be destroyed after seven years by document shredding. If you have provided any material objects (resources) for consideration these will be returned to you within two weeks of the exchange.

Contacts

You may contact myself at [redacted]

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

<u>Interview:</u>

Name of Participant	*Signature*	*Date*

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix G

Recruitment Material for Primary Participants - Poster

Do you live with advanced breast cancer as a chronic illness?

Do you live in Central or Southern Vancouver Island (excluding Greater Victoria)?

Are you interested in participating in healthcare research that will provide insights into the everyday life of women living with advanced breast cancer as a chronic not acute health condition?

Are you living relatively well with a diagnosis of advanced breast cancer (stage 4 or metastatic) and have done so for at least two years?

I am looking for individuals who have lived with having the diagnosis of advanced breast cancer for at least two years and are not in active health decline.

If you think you might be interested in participating in this research, please contact me for further information:

Sheryl Shermak — Doctoral Candidate
Interdisciplinary Studies
Nursing, Home Department
University of Victoria

email: [redacted]
Ph: [redacted]

University of Victoria
School of Nursing

Appendix H

Recruitment Material for Primary Participants — Content for Article in Local Newspapers

Are you interested in participating in healthcare research that can provide insights into the everyday life for women living with noncurative breast cancer as a chronic not acute health condition?

Sheryl Shermak is an interdisciplinary doctoral student at the University of Victoria. Her research interest is people's experiences of living in small community with chronic forms of life-limiting or serious illness. Her doctoral research project is exploring a historically recent phenomenon: women's everyday lives with advanced breast cancer as a chronic condition.

In the communities of Central Vancouver Island, she is seeking the participation of women who were diagnosed with advanced metastatic breast cancer at least two years ago and are not experiencing active health decline, for example not receiving end-stage palliative care. that is women who are living relatively well with advanced breast cancer.

The research goal is to increase insights into the lives of women who experience metastatic breast cancer as an ongoing health condition, an often hidden group of women with breast cancer.

If you think you might be interested in participating in this research, you can contact Sheryl at [redacted]

Appendix I

Script to Invite — Primary Participants (Telephone)

Hi, thank you for calling about the research study on living with advanced breast cancer as a chronic illness.

I would like to introduce myself and the study. At any time, please jump in with any questions or comments you may have.

My name is Sheryl Shermak and I am a doctoral student at the University of Victoria. My doctoral program is in interdisciplinary studies, with my home department being nursing.

As part of my doctoral research work I am conducting a study on the living with advanced breast cancer. The study is formally called: Embodying Living ⇔ Dying: Everyday Life with Metastatic Breast Cancer as a Chronic Illness.

This study has grown out of my curiosity about how advanced forms of breast cancers are one example of illnesses formerly associated with end-stage or terminal disease, but now have the potential to be a condition that people live with for many years.

The purpose of this research project is to address the fact that in healthcare and in health research, the daily experiences of women living long-term with advanced breast cancer are not well-understood, particularly of those in non-urban or rural communities. This study focuses on the dynamics of daily life that help shape women's identities as individuals with serious illness. The hope of this study is to increase insights into the lives of women who experience advanced breast cancer as an ongoing health condition.

Does this study seem like it would be of interest to you?

To participate in this study:

- you need to have been diagnosed with non-curative advanced breast cancer at least two years ago

- not be in active health decline, when I speak of active health decline here I mean not receiving end-of-life care for deteriorating end-stage illness

    - it is recognized that your health or life circumstances may change over the course of your participation, in which case we will have discussion as to what would be best for you in terms of study participation (for example, leaving the study or if staying accommodations)

- living in one of these small communities: Port Alberni, Qualicum Beach or Parksville

It is also recommended, that you reflect on how comfortable you are talking about details of your daily life with illness and whether a research study is the best context for such discussion. Further, discussion of your experiences may involve emotional discomfort. In thinking about this possibility, what are supports you have in place and if there are gaps what can be done to have supports in place? What might I do to assist you?

[If the person inquiring does not meet study criteria I will thank them for their interest and if appropriate direct their inquiry to community supports — this would depend on their individual needs and particular community, but might include the local hospice organization (e.g., Oceanside Hospice in Qualicum), free community counseling services (e.g., Society for Organized Services in Parksville), or the local Canadian Cancer agency office]

[If the person inquiring meets criteria …]
I invite you to participate.

Study participation would involve conversations about your experiences of living with chronic advanced breast cancer. ~~Specifically:~~

Including, two face-to-face interviews, each about one hour, and being invited to share artifacts or objects that help bring to life your story. You would also be given the option to write a brief account of your everyday life with a chronic serious illness.

A brief follow-up conversation by telephone would conclude your participation. A conversation in which I would inquire about any further comments and invite discussion on preliminary study findings. This phone call would occur at a mutually convenient time, hopefully three weeks after the end of the interviews.

I anticipate your time commitment would be spread over a two-month period and be about 4–5 hours in total.

Before the study begins I would mail you the consent form, which contains further details on participation.

Do you have any questions about participation at this time?

By having this telephone conversation about the study with me, you are by no means obligated to participate in this research project.

Thank you for considering participating in the study.

Your participation would be an important contribution into research on living with advanced illness as chronic illness and help health care professionals to understand the realities of living with chronic advanced breast cancer.

[If they agree then I would provide my contact information, ask them for their contact information and inquire if they would like to arrange a time to meet at this time.]

Appendix J

Questions and Topics to Guide Study Interviews — Primary Participants

Note: The purpose of interview questions is to facilitate a discussion about living and dying with metastatic breast cancer. As this is a qualitative research study, application of interview questions is iterative. In this specific case, they will also be applied with sensitivity to the health of participants. There is a guiding plan, but application of questions will be flexible to interview flow and participant needs.

The overall structure is this: The first interview will start with the opening question. The second interview will begin with a broad overview of the first interview and an invitation of any further questions or comments. At the start of this interview, participants will also be invited to share any objects and written work they have. At the end of the second interview the closing question will be applied.

The flexible plan for topics is: Interview one will cover the topics of diagnosis and community. The second interview will cover topics of everyday life and approach to living.

An Opening Question

If we take this interview as a time for reflection and a chance to think about living with a serious illness over a prolonged period of time: What would you have to say about living with advanced breast cancer for this long?

Diagnosis as Entry into Advanced Illness — Prompts:

[The purpose of this set of questions is to explore the beginnings of becoming a person with advanced cancer, a life-limiting illness.]

Before your diagnosis, what did you imagine advanced breast cancer to be? What did you imagine living with this condition might involve?

During the period of time when you received your diagnosis, what did medical practitioners tell you about the prognosis and the outcomes for your illness?

When first faced with the news of your diagnosis, in what ways did you come to learn about what it meant to live with advanced breast cancer?

How has your understanding of advanced metastasized cancer changed since the time of your diagnosis?

How does your current understanding of advanced breast cancer compare with the understanding of advanced illness you had at the time when you were treated for primary breast cancer?

Community — Social Spaces — Prompts:

[The purpose of this set of questions is to focus on the immediate lived contexts of illness that individuals are immersed in.]

How does living in your particular community impact you as a person with advanced cancer?

- Challenges?
- Benefits?
- Curiosities?

What do you think might be different if you lived in a large urban community such as Victoria?

As a person with advanced cancer do you identify with any particular groups or communities? Whether in your local area or through social media?

If you were to imagine an ideal community for your particular health-related needs, what would that look like?

Everyday Life with Life-Limiting Illness — Prompts:

[The purpose of this set of questions is to explore particular events of daily life.]

In your daily life, how does your illness impact how you live?

What does a typical day look like?

In living with your illness, are there times when you feel more visible as a person with serious illness than other times?

What are events or information that stand out for you that changed how you think about your illness?

How has your understanding of what it means to be a person living with advanced illness changed over time? As a person with breast cancer?

Approach to Living with Disease — Prompts:

[The purpose of this set of questions is to explore resources individuals engage with or don't.]

How have you worked towards fashioning a life that allows you to live well with advanced breast cancer, an unpredictable and mysterious medical condition?

How do your current strategies and resources for navigating illness compare with those you accessed during the early stages of cancer, when your disease process seemed acute?

    Are there resources you avoid?

Living with advanced breast cancer disease over time, in what ways has your relationship with your medical service providers changed?

    Relationships with other key informants of your life with illness?

A Closing Question:

There are ways that your healthcare providers, the media, friends, and family speak about advanced breast cancer. And ways they speak about serious illness. After these years of living with advanced breast cancer for yourself how would you define your disease/illness to others?

Appendix K

Verbal Script — Follow-Up Telephone Conversation with Primary Participants

I want to thank you for participating in the study and for sharing your experiences of metastatic breast cancer as chronic illness.

In looking back in the time we have spent together in this project and looking forward to how your stories will be an integral thread in this research, I want to now provide space for further reflections and comments.

(Opening the space for discussion.)

I want to thank you again for your participation.

If you have any further questions or comments you are welcome to contact me at the contact information I have provided.

Appendix L

Sketches of the Women who Participated in this Project (Presented in Order of Project Participation).

Kristin: She is in her early forties. She was diagnosed with stage four breast cancer three years ago and has had no prior history with breast cancer. She had surgery and chemotherapy. She had still been breastfeeding her youngest child before treatment. She is currently still on her first hormone therapy, and she is aware of what the second will be when this one stops working. She lives with her husband and her two young children in a suburban house. She is a high-level professional who has recently scaled back to part-time employment. She is a volunteer for a non-profit society providing telephone support to other women with advanced cancers.

Lorraine: She is in her mid-seventies. She was diagnosed with MBC four years ago after having pain in her hip. She had primary breast cancer over a decade prior. She is on hormone therapy and takes high-dose calcium. She lives with her husband in a suburban house. She has been retired for some time. She has been an active senior who, until recently, spent time in the Southern United States each winter. She has mobility issues and pain in her joints, yet she has found many ways to remain part of her local community. She is currently heavily involved in her local breast cancer support group.

Meredith: She is her early seventies. She was diagnosed with MBC three years ago. At the time of diagnosis, she had surgery and declined chemotherapy because she had watched her husband become very ill from it during his own time with advanced cancer. She is currently on her second hormone therapy. Since shortly after diagnosis, she has been a designated palliative patient and because of this, the local Island Health Home and Community Care office follows her closely (including a nurse who tracks her healthcare plan). She is a widow who lives alone in her own home in a strata development. She has been retired for some time. However, her previous career as a nurse assists her in navigating life with MBC.

Simone: She is in her late thirties. She was diagnosed with stage four breast cancer three years ago and has had no prior history with breast cancer. There is an extensive history of breast cancer in her family, and she has always had a heightened awareness of her body. Her breast cancer was not caught early for several reasons, including being nine months pregnant at the time. She and her family moved from Northern Canada following her diagnosis so that she could have better access to care. Her oncology care is directed out of BC Cancer Agency Vancouver, and she said that her status is considered palliative. Prior to treatment for MBC, her pregnancy was induced. She has since had surgeries, including radical brain surgery, and an aggressive trial chemotherapy plan. She is currently on her second novel therapeutic. She lives with her husband in a new housing development with their two small children. She was an editor. Despite being in relatively good health, she can no longer work because of cancer-related cognitive issues and fatigue.

Morven: She is in her late seventies. She was diagnosed with MBC nine years ago and was told conflicting stories about prognosis, with one being that she had 6–12 months to live. She had a partial mastectomy years ago as treatment for primary breast cancer. In between her primary breast cancer and MBC, she had a broken hip from bone weakness connected with breast cancer. For MBC, her treatments have been not as intense, with radiation at the start and one hormone therapy that she has been on for the entire time. Her medical team considers her to be in excellent health, although she has fatigue, and she needs to walk with canes because of chronic issues with her repaired hip. She is a widow who lives alone in her family home on a small acreage outside of town. Years before her MBC diagnosis, complications from breast cancer led her to take early retirement. She is a pioneer in the breast cancer dragon boating movement, who is no longer active in any breast cancer advocacy and instead supports other seniors in her community.

Mildred: She is in her mid seventies. She was diagnosed with MBC over four years ago. One doctor told her she needed to check off her bucket list, while another told her she had 2–5 years. She had a primary breast cancer 13 years earlier, and she was not expecting a recurrence. At diagnosis, she was treated with an experimental high dose of therapeutics and surgery. Since then, she had been on two different novel therapeutics, sequentially. However, when she developed cancer in her bile duct, her drug therapy was stopped by BC Cancer Agency because they said it was not working. She is now on a hormone therapy that she needs to pay for privately ($4000 a month for which her medical insurance covers 75 percent). She still lives in the community where she was born. She has written her obituary which will not mention cancer because she wants to be known for her roots. She lives with her husband in the family home. She had been a business owner. In her subsequent semi-retirement, she was employed in a less demanding job but has since taken medical leave.

Pearl: She is in her late sixties. She has a family history of cancer that has led her to have regular cancer screening most of her adult life. Twenty-six years ago, she had primary breast cancer where two kinds were found, and she had successful treatments, including removal of a breast. However, eighteen years ago, she was diagnosed with what was described to her as a slow-growing form of MBC. She has been on Tamoxifen since shortly after diagnosis (1999). She has chosen to do genetic testing, and a specific gene was identified. She lives on acreage in a farmhouse with her husband and cats. She has spent her life focused on family. In her family, she has become a dedicated educator of the genetic cancer that is part of their shared history.

Toni: She is in her early forties. She was diagnosed with MBC four years ago and has had no prior history with breast cancer. It had spread into her liver. However, it can no longer be detected there. At the time of her diagnosis, she was taking in vitro treatments with hopes of a second child. She started cancer treatments with a mastectomy and a year of chemotherapy. For the last three years, she has taken a hormone therapy and is on her 64th course. She has radiation as needed. She lives with fatigue, mood issues and weakness in her dominant arm. She is prone to serious infections, and about every six months, she has a health crisis. She lives with her husband and young child in a suburban house. She is a self-employed artist who recently has stopped taking large-scale commercial contracts because they are too taxing on her health. Her art has been a constant thread throughout her life, and it is one thing that is her anchor in living with a life-limiting illness.

Cynthia: She is in her early seventies. She was diagnosed with advanced breast cancer twenty-two years ago and was told to get her affairs in order. She has had no prior history of breast cancer. Her history of treatments includes Tamoxifen, radiation, high-dose chemotherapy and breast surgery. She rejected breast reconstruction because she wanted not to disturb the healing she had achieved and to move on with what her life would be. Seven years ago, she withdrew from cancer screening and cancer therapies. She has unexplained body aches in multiple areas and lymphedema. She lives with her husband in a suburban family house. Up until recently, she had been a long-running organizer in her local breast cancer support group.

Adrienne: She is in her early fifties, and she has had MBC for over two years. She has had surgeries and many radiation therapies. She recently started a clinical trial of two therapeutics and chemotherapy. This programme replaces a previous hormone therapy. Her clinical trial means that unlike most other women in the project, a medical team followed her closely, including a clinical trial nurse. She was also starting a cutting-edge treatment plan for brain metastasis, including targeted radiation by a specialist in Vancouver. Referring to the cutting-edge therapeutics she has been part of so far, and in such a short time, she said she is now a "guinea pig." Before MBC, she had no significant health diagnoses. Her main health concerns are poor energy levels and balance issues, both of which slow down her active lifestyle. She and her husband live in a West Coast log cabin in the woods. They share their home with two older teenagers and a dog who is a beloved hiking companion. was a high-level professional whose career involved international travel, but she has since left work to focus on health and personal development.

Diane: She is in her mid-sixties. Diagnosed with MBC two years ago. She has a prior history of bilateral breast cancer, and she has had highly invasive surgeries, chemotherapy and radiation. For MBC, she has been on a hormone therapy involving an infusion every few weeks at a clinic. She and her husband are homeowners on a Gulf Island, one that has direct access to Vancouver Island. She is retired and has an active lifestyle, including gardening and road trips with her husband in a much-enjoyed sports car.

Janice: She is in her early seventies. She was diagnosed six years ago and was told she had six months to live. She has had chemotherapy and is on her third hormone therapeutic.

Her main problems with MBC are fatigue and fluid-build up in her lungs because of cancer spread. Very occasionally, she needs to have drainage of her lungs. However it can be several months without needing to do so. She lives with her new husband in a small home in a wooded senior-oriented modular park. She has not worked for many years, and she is an active senior involved in many activities. She has a bold, brassy kind of humour that can make her larger than life. By chance, about six months after our interviews, I met her husband, and he told me that she had passed away suddenly (just as she had hoped to do and following another cruise at that).

Darlene: She is in her mid-fifties. She was diagnosed with a rare form of MBC two years ago. No prior history with breast cancer. She is considered palliative, but not currently a palliative client. She has had multiple surgeries, including removal of a breast, extensive radiation treatments, and is currently receiving therapeutics. Her medical surveillance is from more than the BC Cancer Agency, including an as needed relationship with MD Anderson clinic in the States. She has numerous problems with lymphedema. She lives in a rural area with her husband in a new housing development. She is a high-ranking government employee who is employed full-time and travels as part of her work. Connected with her career and as a high achieving person, she was one of the few women to speak of the importance of remedying an altered body. She had a compilation of lymphedema sleeves, wigs, and other strategies to maintain her public appearance.

Sofie: She is in her early seventies. She was diagnosed with MBC three years ago. At the time of diagnosis, she has just passed her five-year anniversary of recovery from a primary breast cancer and was shocked by the news. She is currently on a hormone therapy and is getting staged for radiation therapy. Her therapeutics raise questions that she still struggles with at times. For example, she knows she has a cancer in her cheekbone, yet she is not sure it is breast cancer. She lives with her husband in a West Coast cottage home on one of the Gulf Islands that has direct access to Vancouver Island. She has been retired for many years and has lived a very health-conscious, active life with roots in her European upbringing.

Appendix M

Excerpts of Transcription Style

Example of emotions retained in text. (Participant 3, Interview 1, Page 3)
P: Honestly, I kind of live in the now. I don't even know what I did today. (laughing)

Example of a line of dots used to indicate a weighted pause in the conversation. Note how they do not conform to an elliptical. Also note how text around the dots was not tidied up, instead, left fragmented. (Participant 9, Interview 2, Page 4)
P: [talking about volunteering for the Canadian Cancer Society] So I have my foot in the door still regarding the prostheses, but I no longer do the [whole] extent. You know, at one, time we used to host the doctors from Victoria to run clinics, mammography clinics. We would sit in the mall, and we would sell daffodils, and I just don't ….. I backed right out of it all. I don't campaign when they go.

Examples of square brackets around a blank space used to indicate words that could not be understood on audio and of a vocal gesture that a participant made to augment their spoken words. (Participant 9, Interview 1, Page 26)
P: Yeah, but maybe I didn't need to know it then. But when I had my second breast removed, it's a prophylactic mastectomy. I felt [ ]. So Admissions called and said, you know, it was an optional surgery. So I waited I think 9–10 months for a spot to go in. And I went [coughing noise], "Margot, I have a cold. I can't." And she goes, "Okay. I'll phone you later."

Examples of nonverbal gestures. Also, a time-stamp is included, used to mark the place in audio recording. (Participant 8, Interview 2, Pages 13–14)
P: And told me that she just went to a conference where all the oncologists were talking about this, and they were in tears about how wonderful it works, and you can save people. And she was
00:46:26
like, "You will see the benefit of this drug in your lifetime. You don't need it yet." She told me that on like, Christmas Eve or something. That was like a big [hands up, palms out] confidence booster for me to know that there was this wonderful new drug that they're still learning how to use. If I didn't know about that, I'd be much more fragile, I think.
I: Okay. So that news provided sort of a ...
P: ... confidence. [nodded]
I: ... confidence again.

Appendix N

Questions and Topics to Guide Study Interviews — for Professionals Identified for Inclusion within a Cluster

Note: The purpose of interview questions is to facilitate a discussion about living and dying with metastatic breast cancer. As this is a qualitative research study, application of interview questions is iterative. There is a guiding plan, but application of questions will be flexible to interview flow and participant needs.

The overall structure is: The interview will start with the opening question. At the start of this interview, participants will also be invited to share any objects they have. At the end of the interview the closing question will be applied.

An Opening Question

If we take this interview as an opportunity for reflection: What would you have to say about the experience of living with advanced breast cancer over a prolonged period of time?

Diagnosis as Entry into Advanced Illness — Prompt:

[The purpose of this question is to explore the beginnings of becoming a person with advanced cancer, a life-limiting illness.]

How has your understanding of advanced metastasized cancer changed since the time of ______'s [insert participant's name] diagnosis?

Community — Social Spaces — Prompts:

[The purpose of this set of questions is to focus on the immediate lived contexts of illness that individuals are immersed in.]

In your opinion, how does living in your particular community impact a person living with an advanced form of cancer?
    Challenges?
    Benefits?

If you were to imagine an ideal community for the particular health-related needs of women with advanced breast cancer, what would that look like? For example, optimal care?

Compared with your community, what do you think might be different for women with chronic metastatic breast cancer who live in a large urban community such as Victoria?

Everyday Life with Life-Limiting Illness — Prompts:

[The purpose of this set of questions is to explore particular events of daily life.]

Given _____'s [insert referring participant's name] experience, what are events or information that stand out for you that changed or challenged how you think about advanced breast cancer?

____ [insert referring participant's name] is living well with advanced breast cancer and often seems like she is doing well to others, are there times you can think of where _____ [insert referring participant's name] is more visible as a person with serious illness than other times?

Approach to Living with Disease — Prompts:

[The purpose of this set of questions is to explore resources for disease navigation.]

When you think of someone who is living well with advanced breast cancer and has done so for an extended period of time, what strategies and resources for navigating the advanced breast cancer experience would you consider invaluable? Ones that might not be as important for women dealing with acute and diminishing disease.

Are there resources you think are to be avoided?

In thinking about living with advanced breast cancer disease over time, in what ways has your relationship with _______ [insert referring participant's name] changed?

A Closing Question:

There are ways that healthcare providers, the media, friends and family speak about advanced breast cancer. And ways they speak about serious illness. With your experience over the last few months or years of bearing witness to advanced breast cancer, how would you define this disease/illness to others?

Appendix O

Questions and Topics to Guide Study Interviews — for Non-Professionals Identified for Inclusion within a Cluster

Note: The purpose of interview questions is to facilitate a discussion about living and dying with metastatic breast cancer. As this is a qualitative research study, application of interview questions is iterative. There is a guiding plan, but application of questions will be flexible to interview flow and participant needs.

The overall structure is this: The interview will start with the opening question. At the start of this interview, participants will also be invited to share any objects they have. At the end of the interview the closing question will be applied.

An Opening Question

If we take this interview as an opportunity for reflection: What would you have to say about the experience of living with advanced breast cancer over a prolonged period of time?

Diagnosis as Entry into Advanced Illness — Prompt:

[The purpose of this question is to explore the beginnings of becoming a person with advanced cancer, a life-limiting illness.]

How has your understanding of advanced metastasized cancer changed since the time of ______'s [insert referring participant's name] changed diagnosis?

Community — Social Spaces — Prompts:

[The purpose of this set of questions is to focus on the immediate lived contexts of illness that individuals are immersed in.]

In your opinion, how does living in your particular community impact life with advanced cancer?
    Challenges?
    Benefits?

What do you think might be different if you lived in a large urban community such as Victoria?
If you were to imagine an ideal community for the health-related needs of chronic metastatic breast cancer, what would that look like? For example, optimal care?

Everyday Life with Life-Limiting Illness — Prompts:

[The purpose of this set of questions is to explore particular events and uncertainties of daily life.]

For ____ [insert referring participant's name], what is your understanding of what a typical day looks like?

[If the participant is living with the referring participant or is regularly involved in the referring participant's daily life] In your daily life, how does ______'s [insert referring participant's name] changed illness impact your everyday life?

____ [insert referring participant's name] is living well with advanced breast cancer and often seems like she is doing well to others, are there times you can think of where _____ [insert referring participant's name] changed is more visible as a person with serious illness than other times?

What are events or information that stand out for you that changed how you think about advanced breast cancer?

Approach to Living with Disease — Prompts:

[The purpose of this set of questions is to explore resources individuals engage with or don't.]

[If participant lives with or has a close relationship with the referring participant.] How have you worked towards fashioning a life that allows you to live well as you accompany someone who has advanced breast cancer, an unpredictable and mysterious medical condition?

How do your current strategies and resources for navigating or understanding the advanced breast cancer experience compare with those you accessed during the earlier stages of _____'s [insert referring participant's name] changed cancer, when her disease process seemed acute?

Are there resources you tend to avoid?

A Closing Question:

There are ways that healthcare providers, the media, friends and family speak about advanced breast cancer. And ways they speak about serious illness. After these years of living with advanced breast cancer within the realm of your personal experience how would you define this disease/illness to others?

Appendix P

Script to Invite — Existing Participants to Engage in Building a Cluster (Telephone)

I want to thank you again for your participation in this study.

I am calling today, because I would like to do further inquiry that will help to better illuminate your experiences.

Would you be interested in identifying at least two people, who you would say understand your everyday life with chronic cancer well and/or provide you with the supports you need to navigate your illness well?

The purpose of this inquiry is to provide further collateral information that will enrich analysis of he material you have already shared.

[If the person wishes to engage in this inquiry or has further questions …]

For your information, study participation would involve the identified individuals having a conversation about their experiences of chronic advanced breast cancer. There would be one face-to-face interview and an invitation to share artifacts or objects that help bring to life stories that are shared.

I anticipate the time commitment would be about one hour in total for individuals you know professionally and no more than two hours for people you know personally.

Do you have any questions about the inquiry at this time?

By having this telephone conversation about the study with me, you are by no means obligated to participate in this inquiry.

Thank you for considering further involvement in the research study.

As always, your participation is an important contribution into research on living with advanced illness as chronic illness and help health care professionals to understand the realities of living with chronic advanced breast cancer.

[If they agree then I would provide my contact information, ask them for their contact information and inquire if they would like to arrange a time to meet at this time.]

Appendix Q

Script to Invite — Cluster Interview: Version for Professionals (Telephone)

Hello, my name is Sheryl Shermak and I am a doctoral candidate at the University of Victoria. I am calling today because you have been identified by someone who has advanced breast cancer as in important support person in his or her life and someone with knowledge of metastatic breast cancer lived as a chronic condition.

I would like to introduce myself and the study. At any time, please let me know of any questions or comments you may have.

As part of my doctoral research work I am conducting a study on the living with advanced breast cancer. The study is formally called: Embodying Living ⇔ Dying: Everyday Life with Metastatic Breast Cancer as a Chronic Illness.

This study has grown out of my curiosity about how advanced forms of breast cancers are one example of illnesses formerly associated with end-stage or terminal disease, but now have the potential to be a condition that people live with for many years.

The purpose of this research project is to address the fact that in healthcare and in health research, the daily experiences of women living long-term with advanced breast cancer are not well-understood, particularly of those in non-urban or rural communities. This study focuses on the dynamics of daily life that help shape women's identities as individuals with serious illness. The hope of this study is to increase insights into the lives of women who experience advanced breast cancer as an ongoing health condition.

Would you be interested in a focused, conversation with me about the topic of advanced breast cancer as a potential chronic illness?

I anticipate your time commitment would be 30–60 minutes in total.

A final thought for you to consider: if you chose to participate, although there will be efforts to protect your anonymity and confidentiality, you may be quite identifiable to the individual who recommended you to this study.

[If the person accepts …]

I invite you to participate.

Study participation would involve conversations about your experience on everyday life with advanced breast cancer. Including, one face-to-face interview, about one hour and being invited to share artifacts or objects that help bring to life the stories you share.

Before the study begins I would mail you the consent form, which contains further details on participation. This would give you details as to make a more informed decision on whether you wish to participate.

Do you have any questions about participation at this time?

By having this telephone conversation about the study with me, you are by no means obligated to participate in this research project.

Thank you for considering participating in the study.

Your participation would be an important contribution into research on living with advanced illness as chronic illness and help health care professionals to understand the realities of living with chronic advanced breast cancer.

[If they agree then I would provide my contact information, ask them for their contact information and inquire if they would like to arrange a time to meet at this time.]

Appendix R

Script to Invite — Cluster Interview: Version for Non-professionals (Telephone)

Hello, my name is Sheryl Shermak and I am calling because ________ [insert participant's name] has identified you as an important support person in their life and someone with knowledge of metastatic breast cancer lived as a chronic condition.

I would like to introduce myself and the study. At any time, please let me know of any questions or comments you may have.

I am a doctoral student at the University of Victoria. My doctoral program is in interdisciplinary studies, with my home department being nursing.

As part of my doctoral research work I am conducting a study on the living with advanced breast cancer. The study is formally called: Embodying Living ⇔ Dying: Everyday Life with Metastatic Breast Cancer as a Chronic Illness.

This study has grown out of my curiosity about how advanced forms of breast cancers are one example of illnesses formerly associated with end-stage or terminal disease, but now have the potential to be a condition that people live with for many years.

The purpose of this research project is to address the fact that in healthcare and in health research, the daily experiences of women living long-term with advanced breast cancer are not well-understood, particularly of those in non-urban or rural communities. This study focuses on the dynamics of daily life that help shape women's identities as individuals with serious illness. The hope of this study is to increase insights into the lives of women who experience advanced breast cancer as an ongoing health condition.

Does this study seem like it would be of interest to you?

It is recommended, that you reflect on how comfortable you are talking about details of your daily life accompanying someone with illness and whether a research study is the best context for such discussion. Further, discussion of your experiences may involve emotional discomfort. In thinking about this possibility, what are supports you have in place and if there are gaps, what can be done to have supports in place? What might I do to assist you?

A final thought for you to consider: if you chose to participate ,although there will be efforts to protect your anonymity and confidentiality, you may be quite identifiable to the individual who recommended you to this study.

[If the person accepts …]

I invite you to participate.

Study participation would involve conversations about your experiences of living with chronic advanced breast cancer. Including, one face-to-face interview, about one hour and being invited to share artifacts or objects that help bring to life your story.

I anticipate your time commitment would be about 1–2 hours in total.

Before the study begins I would mail you the consent form, which contains further details on participation. This would give you details as to make a more informed decision on whether you wish to participate.

Do you have any questions about participation at this time?

By having this telephone conversation about the study with me, you are by no means obligated to participate in this research project.

Thank you for considering participating in the study.

Your participation would be an important contribution into research on living with advanced illness as chronic illness and help health care professionals to understand the realities of living with chronic advanced breast cancer.

[If they agree then I would provide my contact information, ask them for their contact information and inquire if they would like to arrange a time to meet at this time.]

Appendix S

Letter of Invitation — Key Informant

Dear :

Greetings, my name is Sheryl Shermak and I am an interdisciplinary doctoral candidate at the University of Victoria, housed in the nursing department. I am writing to invite you to partake in a brief key informant interview with me; an interview in support of the doctoral research study I am conducting on living with advanced breast cancer as a chronic illness. The purpose of the study is to increase insights into the everyday lives of women who are living with a chronic or ongoing form of advanced breast cancer.

I understand you are someone in your community with dynamic professional experience in what it is like to live with and manage serious illness. I am interested in what you might have to say about living with advanced breast cancer and/or chronic forms of advanced cancer.

What would a research conversation with me entail? There would be one interview focused on advanced breast cancer as a potential chronic illness and ramifications for the everyday lives of people living with this condition. I anticipate your time commitment would be 30–60 minutes in total. The interview would occur in a place of your choosing.

In addition to one interview, you would be asked if you would like to partake in an optional data gathering activity— for the purpose of providing a comprehensive picture of advanced breast cancer: During the interview, you would be invited to share resources or artifacts that have informed how you understand the experience of living with a serious illness like advanced breast cancer (for example: newspaper clippings, professional practice material website addresses etc.).

If you are considering participating in the study, I will send you the consent form that contains full details on participation. This would give you details as to make a more informed decision on whether you wish to participate.

I welcome any questions you may have about participation or the study in general.

I want to thank you for taking the time to read this letter and I hope you will consider participation in this study. Your participation would be a meaningful contribution into research on living with advanced illness as chronic illness and supporting health care professionals to better understand dynamics of serious illness in our cotemporary society.

If you would kindly let me know if you are willing to consider taking part in an interview, you can contact me at [redacted].

With thanks in advance for your consideration.

Best, Sheryl Shermak.

Appendix T

Questions and Topics to Guide Study Interviews — Key Informants

Note: The purpose of interview questions is to facilitate a discussion about living and dying with metastatic breast cancer. These questions will help expand my research analysis of material shared by women who are living with metastatic breast cancer. As this is a qualitative research study, application of interview questions is iterative. There is a guiding plan, but application of questions will be flexible to interview flow and participant needs.

The overall structure is this: The interview will start with the opening question. At the start of this interview, participants will also be invited to share any objects they have. At the end of the interview the closing question will be applied.

An Opening Question

I am curious about what are your thoughts on metastatic breast cancer in your community and what women's lives are like?

Metastatic Breast Cancer as a Potential Chronic Illness — Prompts

In your practice, do you encounter women living with forms of chronic metastasized breast cancer? And whether yes or not, would you tell me a bit more about your thoughts of what you see in your practice?

How has your understanding of advanced metastasized cancer changed over the course of your practice?

A Closing Question:

There are ways that healthcare providers, the media, friends and family speak about advanced breast cancer. And ways they speak about serious illness. From your particular place of professional practice, how would you define this disease/illness to others?

Appendix U

Analytical Questions

Note: Analytical questions were a provisional, yet crucial, part of the analytical process. I often pencilled questions onto printed transcripts or post-it notes that could be arranged better to track emerging questions. To provide an example of working with analytical questions, I have included a piece of a transcript. For the ease of readership I have bolded the two lines that became a catalyst for analytical questions. Following the transcript excerpt, I present some of the analytical questions. The presentation of these analytical questions is artificial. They were less linear, and they often spiralled off in connections to other text and concepts.

~

[Participant 11 — Diane)

P: I went to see her [general practitioner] the day before we went on vacation, and my tumour markers had been really good. She's been doing my tumour markers every month and they've always been really reliable for me. I had a bone scan, I had had radiation on a couple of places on my back that was really bothering me, and I set myself up for failure. I really thought that she was going to tell me I was stable. And when we got the bone scan, the scan said that my mets were pronounced. So I asked her what that meant. She said, "What do you mean, what does that mean? They're more pronounced." I said, "I thought that I was going to be safe-ish, but no." "We're going to have to talk about going on to the next medication."

So here's my husband and I leaving on our vacation from Victoria, and it just put this huge damper on our vacation because we thought that I wasn't even really getting more than a year out of the first medication. Anyway, we kind of jellied ourselves out of it and we're on vacation. We came back, and my radiation oncologist is much better. I really like her. She's no-nonsense but she's much easier to talk to. She will explain things much better.

Anyway, I had another bout of radiation and a bone scan. And she said to me, "Oh, I can't believe they gave you a bone scan already. That's ridiculous. It's way too soon. Of course your mets are going to be more pronounced because this is what happens when they're healing, and they can't tell the difference."

And I had kind of read this on breastcancer.org [how to read tumour markers]. There's a number of women who are on the same thread, and they had had the same radiation previously, and they said the same thing. **That this is what happens. In their experience, this is what happens. And we know this is anecdotal and it's not studies. But I'm sorry, when you're metastatic you go with anecdotal.**

Analytical Question (initial): What is desire producing when Dianne says, "but I'm sorry, when you're metastatic, you go anecdotal"?

Analytical Question (next]: How does anecdotal information work in her efforts to not be defined by her cancer and her mortality?

> *Analytical Question (next):* How does anecdotal knowledge work with the ways she is mediating the knowledge from BC Cancer Agency practitioners?
>
> > *Analytical Question (next):* How is her association with anecdotal knowledge mitigating fears and uncertainties?

Appendix V

Colour Key for Coding

Notes on development of the colour key: Data analysis was a material process. One raw material was a complete set of printed copies of primary participant interview transcripts. I formatted interviews transcripts to have analytical workspace in the form of a wide righthand margin. Another raw material was an artist quality pencil crayon box with many colour options (hence the names shared in the key below). A less obvious raw material was the audio recordings that I revisited to clarify missing words and to clarify what women hoped to share.

Working towards resonances I applied colours to text within the printed transcripts. I highlighted text of interest, marked supporting text and I added a dot of colour in the margin to easily locate. I often added handwritten first thoughts to the margin. There was one colour per potential subresonance. Over time I had a fairly stable colour key that showed which subresonances held together. The final colour key is:

Temporal Pulses.

Loaded Experiences of Time.
  Distortion: Sky Blue 🟦
  Sequencing: Light Blue 🟦
  Abeyances: Blue 🟦

Frequencies of Presence and Absence at the Same Time.
  Placement : Magenta 🟪
  Ruptures : Red 🟥
  Discord : Mahogany 🟫

Living with Bodily Transpositions.

Navigating without Set Waymarkers.
  Sense of Belonging: Green 🟩
  Body Signals: Aqua Green 🟩
  Tethers: Jade Green 🟩

Enduring: Horizons of Hope and Possibility.
  Small Practices of Mediating Hope: Red Orange 🟥
  Pathways for Living: Yellow Orange 🟧

Appendix W

Example of Mind-Mapping and Diffractive Notes for a Key Informant

- Seeing more women w/ MBC in her practice → echoed by other key informants
- complexification about what is breast cancer → " " "
- a variation of women developing their own protocols was discussed by the GP informant + the internal medicine informant

Appendix X
Mind-Map – "I Am Grateful For" by Kristin