

METASTATIC CANCER AND MOTHERING: BEING A MOTHER IN THE FACE OF A CONTRACTED FUTURE

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Abstract

For the majority of people diagnosed with metastatic cancer, there is little hope of a disease-free future. Drawing on ethnographic fieldwork at a support group for women with metastatic cancer, we examine the relationship between metastases and mothering. We argue that the experience of raising children while living with a terminal illness crystallizes cultural expectations about mothering based on an essentialist model of parenthood whereby the person best suited to raise children is their biological mother. These expectations create an irresolvable gap between discourse and experience that both increases the suffering of women raising children as well as generating an internal hierarchy of suffering amongst women with cancer metastases that hinges on the distinction between those who have dependent children and those who do not.

Introduction

Between 2007 and 2008, the first author (KB) conducted fieldwork at a drop-in support group for women with metastatic cancer held at a local cancer treatment centre in western Canada and facilitated by a professional counselor. Several months into fieldwork, at a meeting with six women and the facilitator present, the following exchange occurred:

The facilitator asks who would like to start. As usual, there are a number of furtive glances around the room and no one seems very keen to speak first. Lara¹ then says something along the lines of “What, no one has anything to share? Well, I guess I’ll begin.” She tells us that she is doing well overall, but that she is worried about Sarah – whose eyes fill with tears as Lara gestures towards her. Brenda picks up the box of tissues off the table and gives it to Sarah, who takes one and sobs helplessly, “I don’t even know where to begin.” It is clear that she both wants and does not want to speak. Sarah begins by saying what a difficult time she is having at the moment – she has just found out that she will have to have chemotherapy and that she can’t face the thought of it at the moment. She sobs that her husband and 12-year old daughter have “hit the roof” about it and she doesn’t want to go through palliative chemo again.

There is a long pause as we sit quietly and register this information. I am trying not to cry at this point, although others have fewer qualms. Brenda then asks (it seems to me more to fill the silence than anything else) what type of chemo drugs Sarah will be on – and Sarah rattles off the names (which

mean nothing to me but I presume have some significance for the other women in the room). Sarah sobs that you go through “so much shit to get a piece of paper” but there are no guarantees about how long you will last. Jodie then says something about how the only guarantee is that you will live long enough to start to see your hair start to grow back. At this point, many of us in the room are crying, too, and Sarah is now crying uncontrollably.

Marjorie notes what a difficult time she had with her chemo – how she put so much energy into fighting that she didn’t give in to the emotional side until after it was finished. However, what has helped her is thinking about her grandmother – who died of the same sort of cancer that she has. Her grandmother went very quickly and she is grateful for the fact that she has been around for longer. She got to see the birth of her two grandchildren and she is thankful for that – tears are in her eyes as she speaks. She then says to Sarah, “However, I’m older than you.” This just makes Sarah cry harder.

Implicit in this dialogue was the particularly devastating impact of metastatic cancer for Sarah: at the age of 44, she was considerably younger than most of the women in the room. However, more than her age, it was her 12-year-old daughter that made her story so heartbreaking. For the assembled women, it seemed that the tragedy of metastatic cancer, where life is foreshortened by disease that is largely incurable, is multiplied when the person experiencing the cancer is a mother with dependent children.

In this article, we explore the impact of metastatic cancer on women like Sarah, who are the mothers of non-adult children. The arguments presented are based primarily on data collected at a support group for women with metastatic cancer between September 2007 and April 2008. The support group was a small, intimate and relatively unstructured affair that met for one and a half hours on a fortnightly basis. Meetings generally attracted between six and twelve women, and just under half of the women who attended the group in the fieldwork period had metastatic breast cancer; the remainder had blood, colorectal, ovarian, uterine, stomach or lung cancer as their primary tumor sites. The majority of group members were in their 50s and 60s, and many had adult children and grand-children. However, four of the regular group members had non-adult children ranging in ages from four to eighteen.

Unlike breast cancer support groups, where there tends to be a strong focus on advocacy (Gray et al. 1996; Klawiter 2008), support groups for women with metastatic cancer tend to focus primarily on dealing with the unique world of ‘mets’. The reality of life with metastatic cancer is that for the vast majority of those diagnosed, there is little hope of a future without cancer. If, as Jain (2007: 84) has argued, “cancer is always about time”, for people diagnosed with stage IV cancer, cancer is *only* about time. Perhaps the greatest challenge for those faced with this diagnosis is coming to grips with the knowledge that it is not a matter of *if* their cancer will kill them, but *when*. Women in the metastatic cancer support group (many of whom had lived as ‘cancer survivors’ before metastasis) often emphasized the distinctiveness of life with ‘mets’ and contrasted it sharply with their prior experience of cancer (see also Vilhauer 2011).

During the fieldwork period, Kirsten attended the support group meetings and other social events, and interviewed most group members about their experiences of living with metastatic cancer. She has continued to remain in touch with the support group, although only a small number of women who took part in the original fieldwork are still alive today.

CULTURAL CONCEPTIONS OF MOTHERING AND METASTATIC CANCER

Mothering has been described as both a biological and moral activity of caring (Elmberger et al. 2005), although how women become mothers and live mothering is greatly determined by larger social and cultural forces (Varcoe and Hartrick Doane 2008). Earle and Letherby (2007) argue that women make sense of the process of becoming mothers within the context of a social time structure that establishes a normative expectation against which to measure their own mothering goals, informed by various discourses that set out how they should behave so as to produce the most desirable characteristics in their children (Lawler 2000). These discourses span the period from the ‘womb to the tomb’ (McNaughton 2011): from when women are pregnant, continuing as they raising children into adulthood (Lupton 1996; Ristovski-Slijepcevic 2011). Indeed, Ruddick (1989) has suggested that the central moral dynamic of mothering is to take upon oneself the responsibility of preserving children’s life and fostering growth in accordance with key cultural values. Keeping a child healthy is thus a key component of the everyday work of mothers (Charles and Kerr 1988; Ristovski-Slijepcevic et al. 2010), one through which their adequacy is judged by themselves and by others.

Although some feminists have suggested that mothering is an action – a practice – that mothers *do* to deserve the title of ‘mothering’ and is therefore, at least theoretically, a de-gendered activity (Ruddick 1989; O’Reilly 2009), in Western contexts mothering is still firmly rooted within an evolutionary and biologically essentialist paradigm. Cultural idioms such as ‘motherly love’ and ‘maternal instincts’ suggest that the person best equipped to raise a child is his or her biological mother (Weiss 1998; Miall and March 2003). Despite shifts to more egalitarian gender ideologies (Kemmer 2000), the practicalities of caring for children often impede this shift and solidify a gendered division of labor at home (Beagan et al. 2008). In consequence, fathers and extended family members continue to be seen as less-than-ideal substitutes for biological mothers,² based on the assumption that no one else can adequately take on the mother’s role.

In light of these responsibilities, what happens when a mother – especially one with dependent children – is diagnosed with metastatic cancer? How is a woman’s experience of mothering transformed in the context of living with a disease that will foreshorten her life? What is it like to parent children when you have been brought into an abrupt and shattering confrontation with your own mortality? We know little in general about the experiences of people living with recurrent and metastatic cancer in the increasingly long period between diagnosis and end-of life (Mahon and Casperson 1997; Howell, Fitch and Dean 2003; Yang et al. 2008; Vilhauer 2008). We know even less about what it is like to mother in the face of a contracted future.

What we do know about mothering and metastatic cancer comes primarily from the burgeoning cancer survivorship ‘self-help’ literature, which periodically

touches on topics of relevance to mothers with children (e.g. Schnipper 2006; Silver 2006). Recently, several volumes devoted to mothers/parents with cancer have also emerged (Russell 2001; van Dernoot 2002; Walker 2002; Blachman 2006). Blogs like 'Mothers with Cancer' (<http://motherswithcancer.wordpress.com/>) also provide a sense of what mothering with cancer is like. As this literature illustrates, when mothers are diagnosed with cancer, one of the first questions they ask is about their children:

When I was first diagnosed with Stage IV Inflammatory Breast Cancer and given a certain prognosis, the first words out of my mouth were, 'but I have a (at that time) six year old son'. My first thoughts were of [her son] of raising him, of wanting to be around for him... I don't know that there is a 'good' time for him to experience more loss, but I want to be there for him as long as I can be (Mothers with Cancer 2010).

If you are a mother it is very likely that, in the first blinding moments of knowing you had breast cancer, your heart and your thoughts went to your children. It was certainly my instant reaction: the heart-stopping fear of leaving my daughters motherless (Schnipper 2006).

I used to want a lot of things. Now [after having had cancer], all I want is to see my children grow up, get married and have children of their own (Mothers with Cancer 2010).

Although the self-help literature provides some sense of how mothers experience life with cancer and metastatic disease, the clinical literature appears generally uninterested in mothers' experiences; instead, it focuses primarily on the impact of a parent's metastatic cancer on the *children themselves* (e.g. Wellisch 1985; Christ et al. 1993; Welch, Wadsworth and Compas 1996; Faulkner and Davey 2002; Huizinga et al. 2003; Rauch, Muriel and Cassem 2003; Christ and Christ 2006). Studies often consider parents' perspectives on their children's adjustment, rather than their own experience of parenting while living with a terminal illness (e.g. Siegel et al. 1992; Welch et al. 1996). This gap in the literature is revealing of clinical conceptions of parenting/mothering. Underwriting the lack of interest in parents' experiences *as parents* is the sense that parents' own needs and concerns are unimportant — that their focus *should* be exclusively on the welfare of their children. This is explicit in some accounts of parenting with cancer, where strikingly judgmental language is used to describe parents (always women in the examples provided) who fail to efface their own needs in caring for their children. For example, in a 1985 article on adolescents 'acting out' when their mother has cancer, Wellisch notes:

Mrs N. seemed a childlike, petulant figure who gave her son two distinct messages in regard to his potentially leaving home and going away to college. On the one hand, she stated to her son, "All boys should go away to college when they are old enough," while later in the session she stated, "How can I possibly get along with you gone?" (pp. 169-170).

Over fifteen years later, Faulkner and Davey (2002) similarly write:

Cancer can lead to parental inaccessibility. Treatment demands or preoccupation with the illness can make the parent physically or emotionally unavailable to the child or adolescent. Overall, parental illness has been found to cause parental withdrawal, indifference, unreliability, hostility, and coerciveness, which are linked to impaired adaptability of the child in the form of behavioural, social, and self-esteem problems (p. 65; see also Sigal et al. 2003).

The message in this literature is clear: parents with metastatic cancer need to place their children's needs ahead of their own. Those parents who fail to succeed in this are 'petulant', 'unreliable', and 'indifferent': 'poor parents' who are jeopardizing their children's social and psychological development, leaving them 'at risk' of maladjustment. Much of the clinical literature also encourages parents to maintain a sense of normalcy for their children. Thus, parenting tips include "Children do best with a regular schedule and should be encouraged and supported in continuing 'life as usual'" (Rauch et al. 2003: 118s), as if this were straightforward when a parent has had her life artificially foreshortened through a diagnosis of metastatic cancer.

Studies comparing children's and parents' assessment of the child's functioning have often found that parents underestimate the impact of cancer on their children (e.g. Welch et al. 1996; Christ and Christ 2006), suggesting that parents' assessments of their children are 'biased' and 'unreliable' – once again implying that parents are failing to meet their obligations to anticipate the needs of their children and to recognize the stress and distress they may be experiencing. Parents are advised that neither the experience of cancer nor parenting responsibilities can be put on hold: "Facing this challenge and finding ways to cope with parenting is not easy. However, you cannot stop parenting while you are dealing with breast cancer; your children still need to be parented" (Corsini 2007: vii).

Although much of this literature discusses the impact of 'parental' cancer on children, in the vast majority of cases, the cancer patients at the center of the discussion are mothers. For example, one literature review of the impact of 'parental' cancer on children and the family (Visser et al. 2004) includes 45 studies, and 84 percent³ involved research where the cancer patients in question were exclusively or primarily mothers. Yet, at no point do the reviewers discuss the gendered composition of the studies, demonstrating how parenting and mothering are collapsed.⁴ In the sections that follow, we examine the ways that women and mothers engage with these prevailing discourses, and examine the experience of parenting when faced with a disease that slowly but doggedly debilitates the body.

METS AND CHILDREN: THE HIERARCHY OF SUFFERING

As the account at the beginning of this article illustrates, within the support group, there was a universal, if largely unspoken, agreement that living with metastatic cancer was far worse when the woman had dependent children. Although something of a taboo topic in group meetings, broached only indirectly in women's accounts, this 'hierarchy of suffering' was something many women invoked in individual interviews. Time and time again, women with adult children echoed their relief that they had not been diagnosed with metastatic cancer until after their children had

grown up. The following exchange occurred with Marjorie, a 65-year-old woman with two adult children, when discussing her reaction to her diagnosis:

Kirsten: But what was running through your head at this point [when diagnosed with cancer]?

Marjorie: The first thing I thought of was “thank God my children are grown.” That was my first thought. I remember I went out into a very sunny day, and I remember looking out there, “thank God my children are grown.” No kidding. Because, you know, I could deal with it.

Maria, another group member with an adult daughter, shared similar sentiments:

Kirsten: So how did you feel after that first meeting, after you went along for the first time? What did you think of it? Do you remember your original impressions of the group?

Maria: I liked it... I remember having a big relief, to see how people could cope... Also you know, the fact that people live with it, and live good lives, productive lives. And see this, a woman who was organizing the bowling [Sarah], she has been fighting it for about ten years, and *she has it ten times worse than I do*, and she still has young kids (emphasis added).

Diana, another group member with three adult children, similarly referenced Sarah’s ‘pain’ when discussing her own children, noting that they were much older than Sarah’s daughter: “My youngest is 35 [and so] I don’t worry so much about them.”

Women in the group shared an understanding that mothers with dependent children had a claim to suffering that ‘trumped’ all other claims women might have, including physical pain (a serious issue for women with bone metastases), disabilities such as blindness, or even *not* having children, although this latter state entailed its own special form of suffering for other younger women in the group. For example, Bridget, a woman in her early 40s, talked about how her diagnosis had forced the realization that time had run out to do the things she wanted to accomplish in her life: “Like, I’ll never be able to have children, and I’m limited to what I can I think have from now to the end of my life. And that is devastating....”

The claims of biological mothers also trumped other kin relationships where women were acting as primary carers for children. For example, on one occasion, Jane, a woman in her 60s, attended the group and had the following story to tell:

All eyes then turn to Jane who starts crying. She tells the group through her tears that she has uterine cancer that has metastasized. Someone asks when she was diagnosed and she indicates that it was in 2005 – although it becomes clear that she only learnt about the metastases in January. She then apologizes for her tears and cries “But I’m just so pissed off” and continues that she is really worried about her granddaughters who are 7 and 9 – both of her own daughters are alcoholics and she wants to be there for her granddaughters.... Lara notes that there are several women in the group with children – although they are not here today because it is Spring break – and how much more difficult it makes things when there are children in the picture. Marjorie then

notes that she remembers that when she got her diagnosis, the first thing that ran through her mind was “Thank God my kids are grown.”

In this discussion, Brenda stated how much more “difficult” cancer is when there are “children in the picture.” However, although people listening to Jane’s story (including KB) were sympathetic, and although it was clear to us that Jane had a fundamental role in ‘mothering’ her granddaughters, it did not have the same heart wrenching qualities as Sarah’s. The hierarchy of suffering therefore appears to intersect with the hierarchy of mothering mentioned earlier, whereby the most appropriate person to ‘mother’ a child is the biological mother, rather than another family member.

Given the perception that adequate substitutes are lacking for the mother of young children who is terminally affected by illness, it is perhaps unsurprising that so much of the support literature about families dealing with cancer either ignores mothers or focuses exclusively on children. Blachman (2006) has suggested that the failure to attend to the needs of mothers is perhaps related to our cultural confusion in conceptualizing motherhood and mortality. In the case where motherhood and mortality intersect, Blachman states that “[i]f being sick is generally depressing and frightening, if cancer raises the specter of death, if death is to be avoided at all costs, then seriously ill mothers of young children strike an emotional chord on an altogether different scale” (p.35) Rauch and Muriel (2004: 38) further note that parenting is rarely raised in clinical settings because “the oncologist finds it too sad to talk with a patient about their children. The oncologist may be reminded of his or her own children, and how distressing it would be to be in the patient’s shoes.” Instead, we choose to live with a “healthy unconscious delusion about the permanency of mother[s]” (Blachman 2006: 35), and hold inflated expectations about mothering. In this framework, mothers give us life, protect us from pain, sorrow and loss; they are strong, reliable and resilient, and do not become ill or dependent. Acknowledging the real experiences of mothers as human beings with the possibility of death, fatigue and failure is unthinkable (Blachman 2006).

Childless women in the group echoed the unthinkability of metastatic cancer whilst mothering young children, readily highlighting the particularly ‘heart-breaking’ nature of a diagnosis of metastatic cancer for such women. For example, Sue, a woman in her 50s, noted:

But I think that the time that I take in the group is not, because maybe, I just – it might be really blunt, I wish I’d shut up sometimes because a lot of people have a lot more important things to say, and a lot more going on than I do... And sometimes I don’t want to go because my heart breaks, and you know, you get close to these people and I just can’t stand [it], like Sarah, right, and she’s got a child and a husband...

Sue explicitly invoked the hierarchy of suffering when she expressed the view that she wished she’d “shut up sometimes” because other women “like Sarah” had more important things to say.

This ‘hierarchy of suffering’ was also articulated by women with dependent children themselves, as the following exchange reveals:

Kirsten: You are in a quite distinctive position in the group because... many of the women in the group, their children are grown. There are a couple —

Sarah: That's an issue.

Interviewer: Right. So can you elaborate on why?

Sarah: Why is that an issue? Well I think, as you put it, *that puts me in a different category than a grandmother*, and meaning no disrespect, you know, but, you know, some of the ladies they have had the honor of raising their children. And I might not, and that's seriously disturbing to me... [I]t doesn't even feel like it's about me anymore. It's not about me, it's about her. And I really believe that, you know, and that's maybe why I can, you know, handle all this torture that's delivered upon me, because it's not about me. I really believe that I have a lot to give to Sally [daughter] and I really believe that she has that right to receive it from me (emphasis added).

Sarah contrasted her own position with that of other women in the group, evidencing the ways that mothers in the group internalized cultural expectations about mothering and the perceived unnaturalness of not raising (or being able to raise) one's own child (Gustafson 2005). Sarah saw her impending death as an active loss, not primarily for herself but for her daughter, and she invoked her daughter's 'right' to a certain maternal lifespan (cf. Jain 2007). Her daughter gave her the strength to "handle all this torture that's delivered upon me" because she needed to survive, not for her own sake, but for her daughter's.

Yet, as Sarah and other women with young children made clear, mothering also has its own rewards. Mothers indicated that young children brought deeper meaning to their lives, helping them to deal with ongoing issues and giving them a sense of desire to get through cancer in order to see their children become independent adults (Blachman 2006; Rauch and Muriel 2004).

Single women often talked of the fact that there were no distractions from their cancer – from the 'dark' or 'black' days. For example, Bridget noted:

You probably won't see the black Bridget. She'll probably be at home in bed, that's the thing. That's where I tend to go.... So you know, I would spend, you know, sometimes on my tough days I would spend the whole day in bed... And those days you just will not see me. I will cancel things and I will stay in bed or stay in the apartment.

While mothers with children did not have the 'luxury' of being able to stay in bed all day, kids help to "pull yourself out of your head" – something many single women struggled with. Clearly, all women in the group, regardless of whether or not they had children, felt that being a mother with dependent children superseded all other sources of suffering to which a woman with metastatic cancer might lay claim. However, the predominance of this hierarchy of suffering silences the 'rewards' of being a mother with dependent children while dealing with cancer.

THE NEED TO MAINTAIN A SENSE OF NORMALCY

In light of the emphasis in the clinical literature on the need for parents to maintain "life as usual" (Rauch et al. 2003: 118s; see also Huizinga et al. 2003), and the dangers attendant in becoming 'preoccupied' with one's cancer, it is unsurprising that

women with families often recounted the expectation to meet their regular responsibilities while living with ‘mets’ and the pressure placed upon them to maintain a sense of normalcy in their households.

For example, Eileen, who started attending the group after fieldwork had been underway for several months, was in her late 40s and recently diagnosed with metastatic cancer. She had a teenage son at university and she was also dealing with the worsening health of her father-in-law, who died during the period she attended the group, prior to her own death six months later. At her first meeting, following some gentle prompting from the facilitator, Eileen opened up about her experience of family life since her diagnosis:⁵

Eileen indicates that after she was diagnosed with metastatic breast cancer, she was still expected to undertake her previous roles. She jokes that the internet and a credit card came in really handy and she hired a cleaner. However, even though she was in a lot of pain initially, it took a while for her husband to register this... Continuing with her point about people you are living with not getting ‘it’, Eileen mentions that just the other day, her son came home at 11pm at night and gave her a list of things he needed for moving out the next day (he is in university and has moved to a frat house). There is some conversation about young adults being self-absorbed and more concerned with how the cancer is going to affect them.

In a support group meeting a few weeks later, discussion returned to Eileen’s responsibilities in the home:

Someone says something to Eileen about the need to ‘make time for you’.

Eileen takes up this point and says in a frustrated voice that people always say that but how can you do that? She has to help others – she has no choice in this... She indicates that it is often just not possible to look after yourself.

What can you do?

Eileen’s sense of frustration at the advice to “make time for you” speaks to the limitations of some of the self-empowerment tropes in the cancer survivorship literature about cancer as an opportunity for a ‘time out’ and ‘emotional makeover’, which several scholars suggest have become hegemonic (e.g. Ehrenreich 2001; Sinding and Gray 2005). One of the central themes of Lynette Walker’s (2002) *Mothering, Breast Cancer and Selfhood* is the idea that breast cancer survivors need to make time to mother ‘oneself’. In this book, Walker differentiates between the ‘All-Giving Mother’ and the ‘Bedrock Mother’ (pp. 182-183). For Walker, the All-Giving Mother is constantly giving to others without receiving. The Bedrock Mother, on the other hand, “cares nothing for pleasing others. In contrast to the kind of mother I was trying to be, she could be as cold-blooded and withholding as the good mother is burning with generosity. She can hate as passionately as the good-mother loves” (p. 183). Walker describes her breast cancer as enabling her to get in touch with the Bedrock Mother and to focus on nurturing herself.

These themes are also evident in the general literature on mothering, which suggests that by mothering others women endanger their own health and they must therefore take the time to ‘honor’ themselves (e.g. Andre 2009). However, while the alternative might include freedom from certain responsibilities, the general lesson presents women with another ‘should’ – mothers ‘should’ take care of themselves

through commonly advised activities such as eating better and exercising.⁶ Such admonishments to make time for ‘you’, and the necessity of taking time out to ‘nurture’ and ‘mother’ oneself, did not ring true for Eileen, or, indeed, many other women dealing with advanced cancer (Ehrenreich 2001). As Eileen pointed out, the demands placed upon her as a mother and a wife did not disappear with her metastatic cancer. She was still expected to meet her responsibilities and attend to the needs of her son and family.

Mothers with cancer grapple daily with how to maintain continuity for their children while their own existence is disrupted by cancer (Bilhult et al 2003; Blachman 2006; Fitch et al. 1999; Helseth and Ulfsaet 2005). The role of being a mother may thus rival all other existential concerns cancer may raise. Despite the number of balancing acts and transitions women may be required to navigate, they often attempt to maintain their parental roles at the same level as before the diagnosis (Billhult et al. 2003; Elmberger et al. 2000; Elmberger et al. 2008). Yet, the need to maintain a sense of normalcy was not merely a result of external pressure. Women often valued their ability to maintain a sense of normalcy for their families and children and to fulfill their domestic duties. For example, a woman posting on the Mothers with Cancer blog (2010) noted:

I am relying more on my nearest and dearest, setting up playdates nearly every day (even though many of them fall through because of illness, mine, theirs, or kids), cleaning the house obsessively (*because God forbid it be out of order should someone drop by; they might suspect I'm struggling*) (emphasis added).

Within the support group, the importance of maintaining normalcy – not only in relation to domestic chores but the mothers’ own *affect* – was highlighted when Sarah talked about sitting down to watch a movie with her daughter following the initiation of palliative chemotherapy to deal with her bone metastases. At one point in the movie, Sarah laughed at the antics on screen and her daughter leaned over and hugged her and said, “It’s good to have you back.” Sarah discussed this incident in a positive way and women in the group responded as such; the feeling of alienation from one’s body was familiar to many group members. However, in Sarah’s case, it was also clear that she needed to be ‘herself’ for her daughter. Sarah also spoke of her need to ensure her illness did not impact her mothering in individual conversation:

I couldn’t, I just never felt that I could allow myself to change too drastically... And I’m constantly bringing up my daughter’s name, but really, she was the focus of everything for me. I totally had to be her mom. And that was all, there’s no question in my mind, as long as I could, I could not allow myself to not be her mother, because if I gave in, if I said ‘Oh, I’m sick’, you know, like, to me, I feel like I’m rolling over and dying and I’m not going to do that.

Other mothers with metastatic cancer talked of trying to maintain their children’s lives as normally as possible and were acutely aware of the consequences of failure:

Eileen then talks about the fact that her husband coaches a lacrosse team and one of the boys in team has recently lost his mother – 5 years after she was diagnosed with cancer. She (or her husband) was talking to the boy about it and the boy indicated that it was “five years of hell.” Everyone in the room is

horrified (but especially Sarah, Lara and Jodie – all the women with dependent children) to hear this, and comment on how awful it is.

Evident in this anecdote and in women's responses to it was a shared belief that despite living with metastatic cancer, life needed to go on 'as usual' – for fear of their cancer being experienced by their family (and especially their children) as 'years of hell'. Yet, while women desperately wanted to ensure their families got along without them, some also expressed ambivalence: that their family would be 'okay' without them was both their greatest desire and worst fear. This ambivalence was evident in Sarah's concern about attending a group retreat:

Michelle asks Sarah if she has decided to go on the retreat this weekend and Sarah notes that she has. Everybody exclaims enthusiastically about this and Sarah responds that she isn't very excited yet and hasn't packed her bags. Michelle mentions that although she is not into reality TV she recently saw a show about a small Canadian town where all the women left for a week and that this situation is kind of like that. However, everyone did cope with the departure of the women. Sarah jokes (as she has previously, so it may not be a joke) that this is what she is worried about – how can she be a domestic 'goddess' if they cope without her while she is gone?

It seems that her fear about her family coping when she was 'gone' related not only to the retreat, but to their life after her death.

'CRAM PARENTING' AND 'MAKING MEMORIES': TEMPORAL DISTURBANCE IN WOMEN'S EXPERIENCES OF MOTHERING

As these women's accounts reveal, mothers in the group felt pressured and placed pressure upon themselves to maintain a life 'as usual' for their families and children, but were simultaneously and acutely aware of the reality that they were now living and parenting in the face of a contracted future. In this context, mothering must inevitably become a race *against* time. Understood in phenomenological terms, the biographical disruption that Bury (1982) suggests is part and parcel of living with chronic illness is manifested as a radical temporal disturbance (Toombs 1990; Brough 2001; Morris 2008).

From the perspective of Husserlian and Heideggerian phenomenology, time is experienced in two distinct senses: natural or clock time and subjective, lived time. Although objective time's inevitable course (i.e. death) usually remains in the background of our experience,⁷ diagnosis with metastatic cancer creates a collision between clock time and lived time, transforming our way of experiencing what is now, past and future – and jeopardizing the openness of the future (Brough 2001). According to Heidegger (1962), the anxiety such a realization produces is positive in so far as it creates the possibility of authentic existence. For Heidegger (1962: 298), "Everyday Being-towards-death is a constant *fleeing in the face of death*. Being-towards-the-end has the mode of evasion in the face of it — giving new explanations for it, understanding it inauthentically and concealing it." Authentic Being-towards-death, on the other hand, and the anxiety it produces, allows Being to "become certain of the totality of its potentiality-for-being" (p. 310).

While many women in the group suggested that confronting their own mortality allowed them to live more authentically, women with young children also

highlighted the *artificiality* of mothering with cancer. On one occasion, conversation in the support group turned to the topic of parenting:

Lara notes that she is mad at her son at the moment... as it now looks that he may not graduate.... She continues, only half joking, that this wasn't part of the deal. She fed him, made his lunch, was his alarm clock for all of those years, and this was the agreement... Lara continues that the problem is that she is 'cram parenting' – trying to cram 20 years of parenting into a couple of years. As a result, her sons feel like she is overly strict and 'mean'. Others in the group clearly like this idea of 'cramming', and Bridget notes that the problem is that this 'cramming' feels artificial rather than organic.

Mothers expressed a sense of inauthenticity in relation to their interactions with their children. Metastatic cancer had forced them to try and 'cram' a lifetime's worth of parenting into a few short years. They had only a short period of time to mould both the present *and* future selves of their children⁸ – something that became clear in the sense of determination that Sarah expressed in ensuring that she, rather than her daughter's peers, determined how her daughter turned out:

Well, now it's different, yeah. She, I'm still just as determined, even though she's going to turn 13 soon!!!...You know, she's still – we're very, very tight, very close. She still, you know, one of the things I think that happens with teenagers is that their peers' opinions become more important than the family, and I'm not allowing that to happen. Trying to make [sure], you know Jack [husband] and I still are more important than the friends.

Women's accounts suggest that in the context of parenting, the usual flow of consciousness is radically altered. In Husserlian phenomenology, past, present and future form an inseparable unit, much along the lines of a melody:

When I hear a melody, I hear not only the present note which is now sounding, but I hear it as succeeding the note just-past which I still retain in my present consciousness. Furthermore, in hearing the present note, I anticipate a future note which will follow it as the melody unfolds temporally (Toombs 1990: 228).

In this formulation, consciousness spans outwards and "takes in the temporal horizons of future and past, against which the temporal object presents itself" (Toombs 1990: 229). However, in the context of parenting with metastatic cancer, to reuse the music metaphor, the mother is listening to a melody where she is attempting to anticipate a distant future note – not the one directly succeeding the present note, but one much farther along. By concentrating on this distant note, the flow of consciousness – the unfolding of the melody – is disrupted.

This situation is complicated by mothers' awareness that their present interactions with their children will one day form their children's memories: their children will look back on present events as 'the past'. Jodie, a member of the group with two young children, talked on a number of occasions about the need to 'create' and 'preserve' memories for her children:

Jodie tells us that she was diagnosed with breast cancer and a short time later found out that it was metastatic. She has two children – one 4 and one 7. She mentions that she has been taking her son to hockey practice – five times in

the last four days. However, she likes this because it allows her to think of other things and it is also an opportunity for creating memories for her son.

However, 'creating memories', like 'cram parenting,' is about trying to create something artificially that is, by its nature, a far more spontaneous process. Women thus live in the present and simultaneously observe their actions from the vantage point of their children's future selves. As Brough notes (2001: 41), cancer "disrupts the ordinary temporal flow of one's conscious life precisely because it focuses one so intensely on what is now, doing so... against the background of one's past and future." For mothers in the support group, present, past and future collapse into each other: the present becomes artificially connected with a distant future in which their children are now adults, and simultaneously a past that their children reflect back on in remembering their mothers and their childhoods.

Unlike their counterparts at earlier stages in the cancer trajectory, mothers with metastatic cancer with dependent children cannot take comfort in restitution narratives (Frank 1995), central to contemporary 'survivorship' discourse, with their underlying supposition that they will become well and able to return to their prior mothering role. As Saillant (1990) has noted, contemporary discourses on cancer center on survival rather than death, and this is central to the therapeutic narratives that structure clinical encounters between cancer patients and oncologists (Delvecchio Good et al. 1990, 1994). For patients with metastatic cancer, this creates an irresolvable gap between discourse and experience that widens as their disease progresses. They are therefore on the receiving end of a paradoxical two-part message (cf. Saillant 1990). For the sake of their children, they must act as if life will continue on 'as usual', emplotting an open future. Yet, they must simultaneously 'prepare' their children for their impending deaths – where "the punch line of the future is dissipated, dissolved into the past" (Jain 2007: 81). That these narratives are mutually irreconcilable is clear in women's accounts.

CONCLUSION

In this paper, we have illustrated how the experiences of women with dependent children living with metastatic cancer crystallize some entrenched cultural discourses on both mothers and mothering. In our view, the *unthinkability* of mothering with a terminal illness (and of children growing up motherless) is strongly connected with the essentialist assumption that no one can take the mother's place in caring for her children after she has gone. These ideas, thoroughly naturalized in the ways that women in the group talked about cancer and children, speak to the ongoing power of cultural idioms such as 'motherly love' and 'maternal instincts', and added immeasurably to the pressures such women experienced in their attempts to care for their children while living with metastatic disease. The internal hierarchies of suffering consequently generated in the group also served to elide other forms of suffering that group members experienced.

Such assumptions pervade the clinical literature on parenting with metastatic cancer. The only alternative discourses available to women via the self-help literature are injunctions to focus on 'you' and to 'mother' oneself, unrealistic admonitions which women in the support group were all too aware carried their own hegemonic tendencies. The idea that mothers with metastatic cancer must *choose* between

mothering themselves and mothering their children paradigmatically connects this discourse with a much larger cultural trope on motherhood and the self: that ultimately women must make a ‘choice’ between themselves (and their career) and their children (e.g. Haussegger 2005). This is a choice, of course, that only becomes necessary in a cultural context where motherhood is synonymous with self-sacrifice.

We have also illuminated several presently under-theorized aspects of the phenomenology of living with metastatic cancer. To date, anthropologists and sociologists writing about cancer have tended to treat diagnosis itself as engendering a radical transformation in one’s orientation to life and death – a state that Jain (2007) terms “living in prognosis” and Frank (1991, 1995) labels entering the “remission society.” However, our research suggests that the distinctiveness of life with metastatic cancer (as a mother with dependent children or otherwise) needs to be more explicitly recognized.

The line between a cancer ‘sufferer’ and ‘survivor’ is clearly an artificial one. As Jain (2007: 77) has noted, it is the prognostic act that transmutes the survivor into a *seemingly* healthy person – asymptomatic but harboring a terminal disease. Yet, while cancer ‘survivorship’ has increasingly become a distinct form of biosociality with its own “medical specialists, laboratories, narratives, traditions and a heavy panoply of pastoral keepers to help them experience, share, intervene in and ‘understand’ their fate” (Rabinow 1996: 102), this has silenced the experiences and voices of those with metastatic cancer – experiences and voices that require considerably more research and reflection.

NOTES

¹ All names are pseudonyms.

² As Miall and March (2003) show in relation to adoption, the idea that biological mothers have a closer bond with their children is still relatively common.

³ The figure is likely higher as the sex of the cancer patient was not reported in all studies. Although the overrepresentation of mothers is at least partially an artifact of the overrepresentation of breast cancer patients in research studies, it is striking how unreflective many of the commentators are about the implicitly gendered representations of parenting their studies entail.

⁴ The father’s perspective during the time of cancer is neglected in the literature (Helseth and Ulfsaet 2005), though rare cases show that fathers are often deeply concerned about how their own (Russell 2001) or their partner’s cancer (Forrest et al. 2009; van Dernoot 2002) may impact their children.

⁵ Women rarely talked about their relationship with their husbands or partners in support group meetings beyond passing references along the lines of Eileen’s comments. Individual interviews with women revealed that there appeared to be some sort of unspoken agreement in the group about avoiding this topic. According to Sarah, “I think that there is never enough time to actually get beyond, to actually get very, very deep. So things like my relationship with my husband, for instance, I would never discuss.” On a slightly different note, Maria noted, “For me personally, you know I am a lesbian but I don’t want to discuss it in front of them. It’s my business.”

⁶ Nurturing oneself in this literature entails its own forms of responsibility, guilt and surveillance (see Bell 2010).

⁷ As Heidegger (1962: 296) notes) “dying is leveled off to an occurrence which reaches Dasein [being], to be sure, but belongs to nobody in particular. Dying, which is essentially mine in such a way that no one can be my representative, is perverted into an event of public occurrence which the ‘they’ encounters.”

⁸ All parents do this to some degree – there is a strong awareness (fostered by parenting manuals and broader cultural conceptions of personality development) that parents’ interactions with their children ‘shape’ them into the selves they will become (see Lawler 2000). However, this awareness becomes particularly acute for parents with metastatic cancer, because of the unique contraction of the present and future that diagnosis with the disease causes.

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