

The incurable self: Negotiating social bonds and dis/connection with metastatic breast cancer

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Abstract

As the culture of silence that once surrounded cancer has gradually given way to greater public awareness, normative visions of what cancer survivorship should entail have proliferated. These visions emphasise positivity and perseverance in pursuit of cure. While these visions provide comfort to many, for people with metastatic cancer the emphasis on cure can undermine their sense of belonging to the broader collective of people living-with cancer. Drawing on semi-structured interviews with 38 Australian women living with metastatic breast cancer, we explore how incurable cancer inflects understandings of self and transforms interpersonal relationships. Extending ideas around biosociality and belonging, we explore the tenuousness of social bonds, revealing how (in)visibility, (in)authenticity and (in)validation circulate within the daily lives of women with metastatic breast cancer. We conceptualise accounts according to four social bonds: (1) threatened bonds where a relationship is strained by misunderstanding, (2) severed bonds where a relationship is ruptured due to misunderstanding, (3) attuned bonds whereby a relationship is based on shared identification, and (4) flexible social bonds when a relationship is based on mutual understanding. More broadly, we illustrate the persistence of normative visions of cancer survivorship and their enduring effects on those whom such visions exclude.

Key words

Breast cancer, social bonds, biosociality, cancer survivorship, advanced cancer, incurability, Australia

Introduction

Since the mid-20th century, a culture of silence, invisibility, and isolation of people with cancer has gradually given way to greater public awareness and new collective identities of cancer ‘survivors’. Constructed around narratives of hope, positivity, gratitude and solidarity, the identity of the cancer survivor has shifted from one of individualised victimhood, to collective positivity, heroism and triumph over adversity (Bell 2012; Klawiter 2008). The cancer survivor identity, however, still represents an idealised experience of early-stage or locally confined cancer, characterised by a linear trajectory from diagnosis, through treatment, towards eventual recovery. Becoming part of a collective with shared experiences of cancer diagnosis, treatment, and recovery, may offer a sense of belonging for some people grappling with cancer. Yet for those living with incurable and progressive cancer, normative expectations and imaginings of cancer survivorship and patienthood may not align with their experiences of cancer, leading to feelings of detachment and estrangement (Steinberg 2015). Indeed, individuals with metastatic cancer may feel particularly isolated by normative visions and detached from the cancer community and others within their broader social networks (Ehrenreich 2009; Kaiser 2008).

In this article, drawing on semi-structured interviews with 38 Australian women, we explore how incurable breast cancer inflects understandings of self, transforming interpersonal relationships as well as embodied experiences of dis-ease. Deploying the concept of social bonds as a framework for exploring these women’s sense of belonging (or not belonging) within the broader cancer survivorship collective, we consider how relationships anchor individuals’ sense of self, especially in times of heightened uncertainty and suffering. Exploring the tenuousness of many of these social bonds and how issues of (in)visibility, (in)authenticity and (in)validation circulate within these women’s daily lives, we illustrate the persistence of normative visions of cancer survivorship and their enduring effects on those whom they exclude.

Background

The biosociality of breast cancer survivorship

Biosociality, a term first coined by Paul Rabinow (1992) describes how people with shared biological conditions come together, build communities and form new shared identities and social bonds, based on their shared experiences of (or predispositions to) illness. While initially applied to new forms of genetic knowledge, the concept has been used to explore breast cancer and breast cancer survivorship as a distinctive form of biosociality (Bell 2014; Klawiter 2008). The biosociality of breast cancer can be traced back to the biomedicalisation of breast cancer in the 1970s and 1980s. At this time, new collective identities and communities were formed for women with breast cancer around shared experiences of diagnosis, treatment and recovery (Klawiter 2008). With origins in the women's health movement, second wave feminism and the fight for reproductive rights, the mainstream breast cancer movement was instrumental in shifting public discourse of breast cancer from one of shame, stigma, invisibility and victimhood towards an affirmative experience characterised by courage, heroism, personal triumph, self-improvement, and transformation (Ehrenreich 2009; King 2006). In the 1980s and 1990s, a new 'environmental breast cancer movement' drew attention to women's social and environmental contexts – not just their individual bodies – as sources of breast cancer risk (Brown et al. 2004). In so doing, this sub-movement attempted to carve out room for creative expression as well as drawing industry and government institutions into the frame of social responsibility and environmental critique (Radley & Bell 2007).

While the breast cancer movement has successfully increased the profile and funding of breast cancer, the ways that breast cancer has been biomedicalised and commodified – e.g., through pink ribbon branding (King 2006) – has produced particular kinds of solidarities and collective identities (Ehrenreich 2009; Sulik 2011). Mobilised around optimism and positivity,

the collective identity of the breast cancer survivor can create a sense of belonging for some. However, scholars such as Ehrenreich (2009) and Klawiter (2008) have *also* been critical of the idealised and universalising category of the ‘breast cancer survivor’. They argue that narratives of hope, optimism, positivity, recovery and triumph invoked by the breast cancer movement, can also serve to silence and marginalise cancer sufferers, especially those whose responses to cancer fall outside the narrow parameters of the optimistic survivor who fights and triumphs over the disease (Bell 2012; Sulik 2011). Furthermore, discourses of determination, battle, future-orientation, optimism and happiness (Bell 2012; Ehrenreich 2009; Guité-Verret & Vachon 2021) permeate beyond the breast cancer community, and influence how those within individuals’ broader social network, including partners, friends, and family members, relate to individuals with breast cancer.

Communities of survivorship and identities of the incurable

Considerable critical scholarship explores how breast cancer survivorship discourses of warfare and positivity can alienate many cancer sufferers/survivors, such as those who have completed treatment, but who live with fear of recurrence (Trusson et al. 2017). Living beyond cancer can be “a persistently disruptive experience” in the lives of cancer survivors long after they have completed treatment (Balmer et al. 2015, p. 468; McKenzie & Crouch 2004). These enduring cancer experiences have potential to marginalise survivors from their ‘before-cancer’ worlds. Yet, while experiences of isolation may be shared by many people affected by cancer, there are also important delineations. While those who have recovered from early breast cancer may live in a perpetually ambiguous state in fear of recurrence (Balmer et al. 2015), those diagnosed with metastatic breast cancer, will live with cancer for the remainder of their lives (Lewis et al. 2016). Thus, they may be left feeling isolated from a community of cancer survivors.

Prevailing cancer survivorship discourses conceal the ongoing presence of cancer in the lives of women with metastatic breast cancer, particularly the uncertainty of living with incurability and the burden and personal responsibility that women may feel to maintain wellness (Sinding & Gray 2005). Reluctance to discuss their cancer diagnosis because of fears of judgement and stigmatisation may serve to impede collectivisation and belonging (Bell 2014), and displays of an authentic self (Goffman 1969). Thus, a diagnosis of metastatic breast cancer may rupture valued social identities and social bonds. Through this severing of bonds, breast cancer may shift from what was a shared experience of social solidarity and feeling of belonging to a survivorship community to an individualised, segregated and invisible experience –a “new closet” (Klawiter 2008). Though there has been considerable research on how early breast cancer affects the lives and relationships of survivors, to date, only limited attention has been paid to how breast metastases affects women’s sense of selfhood and belonging (Steinberg 2015).

Conceptualising biosocial belonging (and exclusion) through social bonds

While Rabinow (1992) and others’ work on biosociality has focused primarily on issues of collective identification, to particular diagnoses, disease status, prognosis and likely (or unlikely) survival, it can be extended also to consider experiences of belonging and exclusion. The concept of belonging has received increased attention across the social sciences over the last two decades (see Allen 2020; Antonsich 2010; Lähdesmäki et al. 2016). Despite the ubiquity of the concept, some scholars have argued that belonging has been “vaguely defined and ill-theorized” (Antonsich 2010, p.644; Kuurne & Vieno 2022). However, advancing theorisation on belonging proves challenging due to its multidimensional nature: belonging can encompass connection to place, collective ideas, material objects and personal relationships (May 2011), as (re)negotiated over time. Building on this scholarship, this article examines relational belonging through the lens of social bonds, that is, by viewing social bonds as the

glue that holds social units together and through which collective identities, communities and societies are created and sustained (Hurtado Hurtado 2021; from a linguistic perspective see Knight 2010). Specifically, we draw on work by Scheff (1997) which distinguishes between secure bonds and threatened bonds (see also Ketokivi 2009). Secure bonds are defined by mutual acceptance and understanding of each other's viewpoint by both parties. In contrast, bonds can be threatened in two ways: in isolated social bonds, where there is mutual misunderstanding or in engulfed social bonds, where one party suppresses their values or feelings in order to be accepted by the other party.

In this article, we focus on the experiences of women with metastatic breast cancer, foregrounding the distinct individual and collective relationships that constitute these women's social worlds. The lens of social bonds offers significant utility in analysing how relationships are in constant flux, ranging from moments and periods of understanding to (mis)alignment and conflict, and how such dynamics evolve in tandem with embodied processes such as remission or progression. Such a processual focus on a range of relationships is difficult to capture by focusing solely on belonging. In line with Ketokivi's (2009) scholarship on peer support and suffering selves, we consider the affective pull of biosocial similarity in moments of suffering and the kinds of social bonds that bind fellow sufferers, as well as how these are negotiated according to dis/similar diagnosis. Unlike social bonds with family or friends, the bond between fellow sufferers Ketokivi (2009) points out, is "a voluntary and openly individualistic bond which one can enter into and exit from at any time, based on the needs of the self" (p. 90). Building on this work, here we examine the social bonds of women with metastatic breast cancer and others within their social worlds, paying attention to how experiences of (in)visibility, (in)authenticity, and (in)validation variously constitute and/or erode social bonds.

Methods

This article draws from a multi-stage qualitative study which sought to document the experiences of women with metastatic breast cancer (Lewis et al. 2021). Metastatic breast cancer (also referred to as stage IV or secondary breast cancer) relates to a cancer diagnosis in which cancer has spread to other organs and is defined as treatable but not curable. The study sought to understand how women experienced living with metastatic breast cancer and the meanings they gave to these experiences.

Ethics approval was provided by the University of New South Wales Human Research Ethics Committee (HC17282). Recruitment materials developed were aimed at women who were 18 years or older who had been diagnosed with metastatic breast cancer. Prospective participants were recruited via advertisements, presentations to cancer support groups, cancer care organisations, advocacy groups and associations, and a cancer wellness centre providing complementary therapies to support people with cancer; direct recruitment via clinicians; and snowball recruitment. A diverse range of women were invited to participate, including those living in metropolitan and regional areas across Australia, those who had been living with metastatic disease for different periods of time, and those who may not have regular engagement with care professionals in formal healthcare settings.

After informed written consent was obtained, semi-structured interviews were conducted by SL either face-to-face in a location convenient to the participant or over the phone. Interviews were guided by an interview schedule co-created by SL who has extensive experience in qualitative research on the lived experience of cancer with input from a metastatic breast cancer consumer. Questions encompassed women's experiences of cancer, the strategies they used to manage their health, and their familial, social and therapeutic relationships. Where possible, participants were interviewed up to three times in a 12-month period, to capture the

interlinked temporal, affective and relational facets of living with incurable cancer, as well as to facilitate rapport-building. Follow up interviews explored if (and how) experiences of cancer and relationships with others had changed. Interviews were conducted by SL between August 2017 and January 2020, were between 30 minutes and 2 hours in length, were digitally recorded, transcribed in full and de-identified. Each participant was assigned a pseudonym.

A constructionist approach to reflexive thematic analysis was adopted (Braun & Clarke 2019) to explore patterns in women's relational experiences and meaning-making. First, we (re-)familiarised ourselves with transcripts and systematically coded data into initial descriptive categories. Next, we generated thematic domains according to the distinct social bonds described by participants, identifying difference, atypical cases and contradictions within the data. We gradually reviewed and refined thematic domains in an iterative process. Throughout the analytic and writing processes, we were in dialogue, reflecting on relevant literatures to make sense of emerging findings.

Results

Interviews were conducted with 38 women. Participants ranged in age from 36–74, length of time since diagnosis (<1–23 years), and educational attainment (see Table 1 for participant characteristics).

INSERT TABLE 1 ABOUT HERE

Across the interviews, the embodied effects of living with metastatic disease were an important feature of women's daily lives. But so too was how living with metastatic disease affected them, and their relationships, in ways that were often independent of their current bodily experience. In the analysis that follows, four social bonds are conceptualised across four thematic domains: (1) threatened bonds strained by misunderstanding; (2) severed bonds caused by misunderstanding; (3) attuned bonds based on shared identification; and (4) flexible

bonds based on mutual understanding (see Table 2 for conceptualisation of these social bonds). Women's social lives were characterised by multiple different types of bonds across different relationships, all of which evolved over time. However, the typology of social bonds characterised below serve as a useful heuristic with the caveat that bonds were not fixed nor mutually exclusive to a particular person or social relationship.

INSERT TABLE 2 ABOUT HERE

Threatened bonds: Negotiating (in)visible and (un)spoken facets of the new self

The first theme developed in our analysis focused on the variety of ways in which social bonds could be threatened in the face of metastatic breast cancer. Here, participants described how the 'suffering self' and associated experiences and feelings were misunderstood, contributing to frustration and loneliness, and strained social bonds. For participants, a diagnosis of metastatic breast cancer marked the emergence of a new self; it was clear that there was no returning to either a pre-cancer self or a future self without cancer. However, others in their lives did not always understand or accept this new self, marked as it was with terminal disease. As Denise, in her sixties and living with metastatic breast cancer for 10 years, articulates below:

People say to me, "So, all good? You're in remission now. You look good. You look well." I say, "Well, yeah, it's all good. But, you know, I'm never going to be in remission anymore." When it's in your bones, it never goes [...] Particularly in the last 12 months, I have been a lot more upfront with people, letting them know that "It is terminal you know. It is stage IV. There will be an end somewhere." (Denise, interview 1 II)

As outlined above, the formation and adjustment to this new self, one bound by a 'contracted future', was often an on-going and protracted process that worked in opposition to normative visions of survivorship (Bell & Ristovski-Slijepcevic 2011). Given the misunderstandings of self, participants frequently discussed being required to inform and educate people within their

social worlds that their illness was incurable, and that it was not a matter of *if* but *when* the cancer would kill them. This set up a tension of (in)authenticity in which participants could disavow their prognosis to maintain a social bond *or* act in a way that was authentic to their new (metastatic) self and risk destabilising their social bond. For example, Joyce, in her early sixties and living with metastatic breast cancer for 15 years, described her friends' enquiries about and misunderstanding around her medication:

They don't realise I've got to be on them [the tablets] forever. I say, "Well, I'm on them until they don't work and then I'll be on something else and something else until it doesn't work at all. It's going to be forever. I'm not going to be cured [...] I think society thinks everything can be fixed, and it actually can't be fixed. (Joyce, I1)

In other cases, the subject of cancer was almost entirely avoided, despite creating an undercurrent within relationships. For example, Kate in her fifties and recently diagnosed, recounted a conversation with her mother who had avoided asking about her illness:

"Mum, I live with that every day of my life. Every waking moment almost, 99% of the time, I'm thinking about the fact that I have metastatic breast cancer. So, whether or not you bring it up I'm thinking about it." [...] She said, "Oh, okay dear. We all do hope you're going to get better." I said, "Mum, there's no cure for metastatic breast cancer. [The oncologist's] best guess is that I will be dead in two years' time." "Oh," she said, "well, we don't really like to talk about that." (Kate, I1)

As Kate's mother makes explicit in this excerpt, talking about incurability and mortality was uncomfortable. However, silence and avoidance around the subject of cancer contributed to the erosion of social bonds between participants and their family members and friends. In a similar vein, Joyce (below) highlighted how a seemingly obvious accessory like a wig went unnoticed or (more likely) unspoken:

I went to a friend's who I worked with [...] I'm sitting there with a wig on and she didn't mention anything. She just completely avoided anything, and I found it really irritating. (Joyce, I1)

Sitting with the unspoken harmed the relational dynamics between Joyce and her friend. The silence was experienced by these participants as the relational other's failure to recognise and accept their new self. These silences often reflected a lack of cultural scripts around non-curative cancer, and mortality more generally. As such, a lack of recognition of incurability, represented a form of 'slow violence', impacting the social bonds of those living with metastatic breast cancer (Barnwell 2019; Nixon 2011).

Social bonds were also threatened by a triangulation of flows of information and updates. A number of participants described how others requested updates about their cancer from their most immediate relations (e.g., their partners), rather than directly from the person living with cancer. Vicki, in her late fifties, and living with metastases for 11 years, recounted how in spite of pervasive silences in conversations with her, questions about her health had been redirected towards her husband.

I think most people sort of don't bring it up. But a lot of them do end up talking to my husband, ringing and checking through him... I asked him, ultimately, for that not to happen so much because I want people to ask me because I'm still quite capable of talking and it doesn't upset me. But they still just check with [him]. (Vicki, I2)

Here upon learning that conversations about her cancer were being diverted, Vicki insisted that she wanted to be approached to discuss her everyday experiences living with cancer. Instead, her explicit request went ignored, resulting in feelings of disappointment and isolation.

Participants felt that others made assumptions about their experience, particularly in relation to how they looked and felt, rather than asking. The chronicity and invisibility of the cancer rendered the experience more isolating. Indeed, assumptions caused loneliness and frustration, as the below excerpts from Nancy, in her sixties, living with metastatic cancer for four years, illuminate:

...as time progresses, they think, "Oh, you're still here, are you? Okay." "Gee, you're looking well. Are you sure you've got cancer?" I could punch people that say, "Gee, you look great." You force yourself to go down the street, because you need to get out of the house, and you feel like back inside every bone aches and you feel sick and they say, "Gee, you look good." (Nancy, I1)

Metastatic disease is very lonely, because you look okay, so people think, oh, you're all right, and you're not. You're sick. You are sick. You're ill. You have an illness and it's debilitating, and people don't understand that. (Nancy, I3)

As illuminated in the accounts above and below, and in part due to the culture of toxic positivity that often surrounds cancer, participants felt that their disease and their suffering selves were erased by people "not understanding" or not "getting it". In this way, participants attributed the disintegration of the social bond to the other actor. But our analysis also revealed how participants limited their self-representation in the company of others, minimising or hiding their experiences and feelings in order to maintain existing relationships and conform to normative expectations. Participants described how they refrained from discussing cancer, as is illustrated by Danielle, in her forties and recently diagnosed with metastases:

You hide how you feel because you don't want to be known as the person with cancer and you don't want to be avoided because you've got cancer. People already avoid me.

So, yeah. You put on that big, happy face. Yeah, a bit like an onion. Like, if you peeled all the layers away, you'd find out what's going on. (Danielle, I3)

Avoiding conversations about cancer and suppressing feelings due to others' expectations was not without consequence, though. Participants explained how this contributed to a disjunction, or, as Elma, in her thirties and living with metastases for 2 years, described it, a feeling of not being able to display an authentic self. Here, Elma describes how one must "put up an appearance" and "be fake", in other words, she deliberately obscures physical and emotional hardship from family and friends in order to be accepted:

I say to [husband] I feel like I need to put up an appearance, as such, and be fake in front of people because at home they don't see what I'm like. They don't see me huddled on the couch in a foetal position crying with [husband] because everything's too hard or I've got chemotherapy tomorrow or I'll do chemotherapy and I feel really sick or, "Why did this happen to me? I still feel really young. Why did I get this sentence?". When I'm out I've got to be brave. (Elma, I1)

Fear and suffering were banished from social interaction and public representations of self (Goffman 1969), but in turn, such omissions undermined and eroded the quality of the social bonds between the women and their important others. Accordingly, women reflected on having to carefully curate their representations of self in line with cultural scripts that link cancer to bravery and positivity, as will be explored more in the following section.

Severed bonds: Relational endings with the evolving/authentic self

The second theme explores what we conceptualise as severed social bonds. Through our analysis, it became clear that for some individuals, relationships that had been mutually beneficial in the past were no longer feasible or worthwhile for a range of reasons. While some relationships continued throughout the evolution of the metastatic self, others proved less

durable and ultimately came to an end. This was notably different from the experiences of connection around early/curable breast cancer that some women reported and reflected on. For example, Lorraine, in her mid-fifties and living with metastases for six years, reflected on her prior diagnosis of early breast cancer and her experience of finding “an organisation of women who always band together” which helped her to “feel good” both living with cancer and living as a breast cancer survivor. However, following a subsequent diagnosis of metastatic breast cancer, she felt a sense of exclusion and (self-imposed) estrangement from people with early breast cancer. From her perspective, the realities of living with metastatic cancer were markedly different to the experiences of early breast cancer and were rendered invisible by the dominance of mainstream survivorship discourse:

I tend to stay away from those people [with early breast cancer] because they don't get it and it's a different world. I know when I was there, I saw people with advanced breast cancer in a totally different category, and now I am there I see them [people with early breast cancer] everywhere. It's a long way away from each other. (Lorraine, I2)

In this excerpt, the repetition of the third-person pronouns “they” and “them” in contrast with the singular first-person pronoun “I” highlights how the participant views non-curative cancer as a distinct identity category in a “different world”, “a long way from” the identity of those with early breast cancer (see also Vilhauer 2011). Metastases impacted how individuals viewed themselves in relation to their broader network of actual or imagined future relationships. In this way, a diagnosis of metastatic cancer was a ‘turning point’ which relationally and temporally reconfigured women’s sense of self (Charmaz 1991). Indeed, following diagnosis, participants often avoided and/or rejected relationships with individuals with early breast cancer as well as connection with the mainstream breast cancer community more broadly.

Participants explained how attitudes of those within the broader breast cancer community were incompatible with the experiences of women with incurable breast cancer. In particular, a dominant discourse within the breast cancer community centred on recovery through active effort and through maintaining ongoing positive thinking. These characterisations were jarring for participants with metastases:

I just really react quite badly to all the, “Well, we’ve had breast cancer and we beat it and we’ve survived. Aren’t we fantastic,” because it almost makes it feel like it’s your fault that you haven’t got on top of this or something... Sometimes I read the stuff that is in the media and on the websites of these breast cancer organisations and there is almost a feeling like if you haven’t beaten your breast cancer you haven’t tried hard enough. (Tammy, I1)

Here, Tammy (in her fifties and living with metastatic cancer for two years) describes how the solidarity within the breast cancer community is fostered through shared beliefs that survival is possible through individual behaviours and interventions. However, for those with a metastatic diagnosis – who will never recover – such responsabilisation and language of survivorship (e.g., messages of positivity and triumph) were damaging and produced feelings of anger, failure and shame.

Participants emphasised how the attitudes described above (i.e., that individuals were responsible and in control of their recovery) permeated wellness culture beyond the breast cancer community. Melissa, in her fifties and recently diagnosed, described how, in past interactions with family and friends, she was expected to make more effort towards her recovery:

I want them to understand that I’m not going to get better and [don’t] expect me to, yeah. You get frustrated with me because I’m not – It’s like as if, “Well, you mustn’t be

trying hard enough or you're not doing the right thing because you're not getting better." [...] You kind of go, "Well, it's not my fault. I tried. It's unpredictable. (Melissa, I3)

The above excerpt reveals how the success of the mainstream survivorship movement in creating collective identities and solidarities for people with early (locally-confined) cancers, may unintentionally alienate and segregate those with advanced, incurable cancers, whose experiences of cancer are enduring and progressive, including within their personal relationships and networks.

Participants expressed discomfort towards social withdrawal – it was not always their desire or intention to end relationships (sever social bonds). But repeatedly encountering the alienating discourse of positivity and survivorship positioned social withdrawal as the lesser harm compared to continuing such triggering interactions. This was intensified by the life-limiting timeframe of metastatic diagnosis – with a finite time horizon, how and with whom to spend that time became a more explicit and value laden choice. The below excerpts from follow-up interviews with two participants reveal how as time went by and they had been living with metastatic cancer for longer, they had become more selective as a form of self-protection:

I'm actually shutting down a bit, I would say, and cutting off [from friends] ... I don't want to waste my time with these people I don't like. People that bother me, I just leave, which is really bad, but I don't care. (Lorraine, I2)

...with a few of my friends, I've stopped seeing them, stopped texting them, and I haven't seen those people now for probably six months. That's okay on my part. They probably wonder where I am. To be fair, they haven't contacted me either. So maybe they get the drift that I just want to be on my own. I don't know. But it's definitely dropped. It's

definitely changed. [...] I'm very careful, I think, with where I go and who I see. (Ellen, I2)

The careful consideration of which friends to continue engaging with resulted in demarcation between “real friends” and those with whom an authentic connection was no longer possible:

I just want to have friends, well, real friends. Someone you can have an authentic relationship, rather than - I don't do superficial (Sandra, I1)

For Sandra, in her fifties and living with metastases for three years, and others, authentic versus superficial relationships was a central tension, highlighting how incurable illness offered a new lens through which to evaluate relationships. In this way, the durability of authentic connection beyond a metastatic diagnosis was something that emerged and became clear over time.

Mis/attuned bonds: Authenticity and mutual understanding (even if only temporarily)

The third theme derived from analysis focused on what we theorise as attuned bonds. While a diagnosis of metastatic breast cancer could test existing relationships with family and friends, it simultaneously created a new type of relationship between ‘fellow sufferers’; that is, between peers experiencing metastatic breast cancer (Ketokivi 2009). While a less common experience among the cohort of participants, some women forged avenues to connect with other women with metastatic breast cancer, such as by identifying metastatic peers at breast cancer support groups or information sessions. Although these relationships were often some of the newest in participants’ lives, they offered women a space and opportunity to openly discuss their experiences and feelings in a way that did not compromise their sense of authenticity. For many, it was *only* with fellow sufferers that a sense of mutual recognition was found.

Participants’ accounts revealed how many were longing to find others also experiencing metastases and that the inability to do so often resulted in feelings of isolation and loneliness. For example, Mary in her seventies and living with metastases for over 20 years recounted:

What I really wanted to do was talk to someone else who was going through the same thing and there were very, very few, because most people didn't have the prognosis that I had. So, I found that a little bit of a lonely experience... I didn't know anybody. I never knew a soul that I could talk to that had exactly the same thing. (Mary, I2)

Here we see how 'fellow sufferers', through shared experience, are the only group of people that together can really understand and bond around metastatic breast cancer. As such, finding a fellow sufferer was positioned as a solution to the loneliness imposed by the illness. This is illustrated by the following participant talking about the benefits of attending a metastatic breast cancer support group:

As soon as you get there and you meet them and people tell their story and you go, "Oh, thank god somebody actually understands exactly what I'm talking about." That being able to identify with and know that these people really get me is a huge relief and it reduces the isolation that you feel. (Tammy, I1)

I try really hard to be true to my own feelings. [...] I don't put on any kind of, "This is how I should be," because everybody knows. The beauty of that group is that you can lay it all bare kind of thing. (Tammy, I3)

Tammy alludes to how peer relationships enable collective sense making and mutual understanding. Through her interactions with peers, her experience was legitimised. In this way, belonging to a collective with the shared experience of metastatic cancer helped ameliorate the socially isolating effects that she experienced after diagnosis.

However, relationships between people with incurable illness bring with them unique complexities, especially as they play out over the complicated timescapes of terminality. Carol (below), in her fifties and living with metastatic cancer for nine years, described the bond shared with her friend built upon a shared openness to mortality and suffering. Notably, the

friends were able to invert their shared pain in humour, distinctively binding them as fellow sufferers (Ketokivi 2009). However, unlike the other types of relationships identified in our analysis, these relationships between those with a metastatic diagnosis had obvious temporal boundaries, with death potentially imminent for each party:

I'd made a really good friendship... and we were really close and we'd catch up weekly. We'd laugh about breast cancer and the bits and pieces that we had to do and when we were going to die and all the rest of it [...] So, she passed in January this year, which was really hard... losing the [person] I could talk to about metastatic. (Carol, I1)

As another participant put it:

[In our support group] we have lost a few of our ladies and we've been confronted with their last few weeks, it does bring it into focus and it does make it real. "Hey, that could be me one day very soon." (Denise, I1)

While many participants said that they found comfort in relationships with those with similar diagnoses, this was not universally true. There were divergent cases in our analysis where participants avoided emotional investment with others with metastatic cancer. For example, Lorraine who had a distinct perspective on peer relationships and avoided the emotional investment:

My feeling is, why would you make friends with them [peers]? They're going to die. It's not something that you want to put yourself through. (Lorraine, I3)

Rather than being a source of mutual identification, recognition or relief, here we see how engagement with fellow metastatic peers was a choice that was too confronting for some, functioning as an overwhelming reminder of the mortality associated with one's condition.

Despite the enhanced recognition that emerged from relationships among women with metastatic breast cancer, there were still limits to their shared experiences, with embodied suffering imposing its own form of isolation. As Tina, in her sixties, living with metastases for 10 years, recognised:

...there is a place in cancer, in the world of cancer that you can't share with anyone. Nobody. Even other cancer people can't get your feelings about your cancer. They can to a degree, but there's a place that you have to deal with things by yourself. (Tina, I2)

Here, Tina explicitly articulated the limits of mutual recognition and identification and the sense of complete isolation and individuality of experiencing cancer. Here, the bodily experience of cancer and psychological experience of facing one's own mortality was experienced as inherently individualising, especially towards the end of life. Positioned in this way, metastatic breast cancer eventually culminates in isolation, whether socially- or self-imposed.

Flexible bonds: Adapting to and validating the new self, living with non-curative cancer

The final theme from our analysis was oriented around flexible social bonds. In spite of the various relational challenges that participants encountered, some participants also described people in their lives (they had known before their metastatic diagnosis) who could recognise their new self – defined by chronic and incurable illness – and adapt their behaviours and interactions accordingly. This required a certain degree of flexibility from both parties to the evolving experiences and feelings associated with metastatic cancer. In contrast to some others who stepped back and created social distance and relational isolation, participants valued those who had “stepped up” to maintain or enhance the social bond between them. In her reflections, Nancy, below, hints at the sense of failure and fault that can accompany the withering of relationships that could not withstand their metastatic diagnosis. But she insists that it is the

others, not the metastatic sufferers themselves, who need to find a way to “deal” with the evolving relational dynamics:

For me, the first thing I found out was that friends will either step up or step back. If they step back, it's not your fault because they can't deal with what's happening to you.
(Nancy, I1)

Across other interviews, participants gave detailed examples of how some individuals within their social worlds made them feel validated and understood:

I'm not able to see people in the way that I could before, like just drop in to say hello, or you go shopping at the same time so you go and have coffee together. Everything has to be planned. So, I've got a few friends who are really good at just sending the occasional text. One has Wednesdays off work. [...] We will often have lunch together on Wednesday. People are adapting for my sake, which is really appreciated. (Janet, I2)

As Janet describes, some friends were able to flexibly adapt to the evolving conditions of metastases rather than remain stuck in the past and attached to the patterns and dispositions of cancer sufferer's pre-cancer self. What characterised flexible social bonds was the others' willingness to quickly learn to modify the space, mode and length of interaction. Participants particularly valued small gestures from others that recognised their limited (and constantly evolving) physical capabilities:

The Sunday before last I had absolutely no energy, I wasn't feeling very well, and Violet said, "Why don't I bring a DVD over?" Now, that's something we've never done before and I thought, "Yeah, why don't we do that?" (Janet, I1)

The above excerpt succinctly captures how to Janet's delight, her friend improvised alternative low-intensity activities that were suited to her fatigue. Being present in new ways, then, was

significant for women with metastatic breast cancer. Similarly, Elma (below) illustrates the value of having one close friend who touches base regularly, keeps communication open and consistent, shows a desire to listen and actively engage with her while only providing advice when elicited:

Anything I need, if I need to talk to her, if I just need to rant she's there for me, she just listens, doesn't say anything. If I need advice, she provides me advice. Every time I've got scans she remembers, messages me, "Good luck with your scans today," and every week for chemo she messages on the day of chemo, "Good luck with chemo today." After chemo, "How are you feeling today?" If we haven't heard from each other for a little bit, she'll message just to say, "Hope you're feeling all right." (Elma, I1)

As evident in Elma's quote above, these flexible bonds, had a liberatory quality. They allowed a space for participants to be angry, frustrated, and sad – to think, feel and act in more expansive ways than those that were prescribed by normative cancer survivorship culture (Bell, 2012). This freedom was particularly important when participants experienced cancer progression or were approaching the end of their life. This was a time when inflexible relationships became more estranged as unpredictable symptoms, cancer progression, and treatment failures required frequent recalibration of relationship with self and with others.

Discussion

This article offers both empirical and conceptual contributions relevant to the field of medical sociology. Firstly, we have explored the lived experience of women with metastatic breast cancer paying attention to how their relationships evolve with and following diagnosis. Secondly, we examined and conceptualised social bonds between women with metastatic breast cancer and others in their social worlds, a novel approach which captures both relational and temporal aspects of belonging. Specifically, the findings of this study build on existing

research on how life-limiting conditions represent a ‘relational disruption’, reconfiguring one’s sense of self and social network (Aasbø et al. 2016; Charmaz 1991). This research emerged from Bury’s (1982) seminal work on biographical disruption, which describes how people with chronic illness experience embodied and relational disruptions that interrupt and reconfigure their hopes for their future (see also Engman 2019). Results reveal that living with incurable cancer changes the nature and importance of social bonds. These changes demand that individuals engage in a continuous process of recalibration of social bonds within interpersonal relationships (e.g., friends, family members, peers) and with collectives (e.g., support groups, breast cancer organisations).

Expanding on Scheff (1997) and Ketokivi’s (2009) scholarship on social bonds, our analysis revealed four distinct kinds of social bonds articulated by participants: threatened, severed, attuned, and flexible. Social bonds were eroded when participants felt that they could not be their authentic self, or their authentic self was not acceptable to (or accepted by) others. In interpersonal relationships characterised by threatened bonds there was a growing gap in understanding between the lived reality of the person with incurable cancer and the external vision of cancer survivorship that they were expected to enact. This gap created a sense of social alienation or exclusion. As such, contexts where participants felt unable to present their ‘true self’, were imbued with negative emotions (Vannini & Franzese 2008). We suggest that the ability to express oneself with authenticity, is a guiding condition which shapes relational experiences post biographical disruption (Bury 1982). These findings align with Ketokivi’s (2009) assertion that “what counts is that there is someone who understands within the reach of the suffering self” (p. 398). In contrast, interpersonal relationships with flexible bonds, allowed for the undulations of living with cancer. This included accommodation of continuously evolving iterations of selfhood and an expansive range of feelings and experiences that encompass the uncertainty, and sometimes suffering, involved in living with

incurable cancer. Such flexible bonds enabled affordances and recalibrations to be made, fostering a sense of security, social connectedness and belonging within relationships. This flexibility was especially important when participants experienced high precarity about their health and longevity.

These findings advance understandings of (un)belonging for those with incurable breast cancer, revealing how *both* sharing the reality of the lived experience and prognosis *as well as* hiding parts of the self to maintain a veneer of wellness and positivity, can serve to isolate and segregate the person from themselves and from others. Our analysis revealed that people living with incurable cancer can find themselves in a lose-lose situation. Irreconcilable in women's accounts was that they must contort themselves to fit within the prescriptive ways of *being* a cancer sufferer/ survivor to ensure social acceptance and inclusion. Yet in performing wellness and keeping hidden some parts of their lived reality that might threaten their social bonds, they risked becoming alienated from themselves. While this can be a protective strategy to preserve social bonds with others, and ward against isolation, it can also amplify the personal experience of loneliness. Alternatively, individuals with incurable cancer can strive for authentic relating, but risk the possibility that others will step back. In both scenarios, loneliness and self- / social-isolation can be amplified. Such tensions resonate with the work of Audre Lorde (1988) who describes her diagnosis of metastatic cancer as “feeling trapped on a lonely star” (p. 85). Lorde articulates the internal struggle of knowing what parts of the self can be shared with others, and what must be kept private, while also recognising that concealing parts of the self isolates and denies others of the (authentic) self (see also Goffman 1969).

Although many participants expressed desire to form community with fellow sufferers with incurable breast cancer, they were not able to establish their own distinct (alternative) biosociality apart from breast cancer (e.g., a collective of “not breast cancer”) as has been shown in other kinds of cancers (see Bell 2014). While bonding with fellow sufferers allowed

women to make sense of their experiences in new ways, these social bonds could also be fragile, temporally bounded by the possibility of sickness and death. They could similarly be inflexible – they were still sometimes bound to particular social rules e.g., assumptions about what is (and is not) helpful for providing a sense of social support while living with incurable cancer as is noted by Ketokivi (2009). This is not to say, however, that early (curative) cancer survivors, necessarily feel a sense of belonging to a shared cancer survivorship identity or are able to form social bonds with fellow survivors. As Trusson and Pilnick (2017) caution, it is problematic to assume the breast cancer survivorship experience is homogenous.

The loneliness and misrecognition that was experienced by women can be interpreted as a consequence of what Bell (2014) terms ‘the breast cancerization’ of cancer survivorship, that is, the harmful ways normative visions of cancer survivorship (and cancer survivors) place constraints on how people living with metastatic cancer, should behave, as well as how others should relate to them. Like people with cancer, those who care and support them are given messages that they should be encouraging, give advice, be optimistic as a way to help those with cancer to move toward recovery and healing. Yet, as Sara Ahmed (2010) describes, while well-intentioned, these forms of recognition (precariously conditional as they are) might ultimately be unhelpful (and potentially detrimental) if they render the person with cancer feeling socially isolated and alone in their experience. Bell and Ristovski-Slijepcevic (2011) found that a diagnosis of metastatic breast cancer forced women to confront mortality and in doing so, contributed to them living more authentically. Our findings suggested a more complex struggle. Participants sometimes concealed parts of the self because they did not want to be defined by a metastatic cancer identity. Moreover, they wanted to protect themselves from further distress or loss (e.g., grief of family members, friends or others with metastatic cancer). This required participants to continuously negotiate the dilemma of (in)authenticity within their relationships, and with whom to share the lived realities of metastatic cancer. How to live

in a way that felt authentic and true to their sense of self – in accordance with their lived experience of metastatic cancer was an ongoing endeavour for these participants; with various consequences for their social bonds with important others around them.

The invisibility of metastatic cancer created the illusion of belonging to the “kingdom of the well” (Sontag 1978, p. 3) or the survivorship community. Yet not being seen or acknowledged enacted a kind of symbolic violence for these women. Indeed, many of the women who chose to participate in this study expressed their desire to do so because of what they saw as the lack of visibility or the silencing of the voices and lived experiences of those with metastatic cancer in cancer survivorship research and policy (see also Bell 2014). Radley and Bell (2007)’s work on the role of artwork produced and used by women with breast cancer as a form of activism is helpful here in thinking about how to increase visibility of those who experience metastatic breast cancer. According to Radley and Bell (2007) making cancer visible requires “ritual practices” that “work on and through” women’s bodies. This “movement from below rather than from the ideology of institutions – involves social relations, discourses and regulatory actions” that constitute changes in normative political visions of breast cancer (p.368). Central to this, is recognition of the importance of establishing visual and discursive spaces for “works of illness” to be produced and displayed (Radley & Bell 2002, p. 370). As such, future research could consider how works of illness can change how metastatic cancer is constituted, as well as offer opportunities for reimagining strategies for living with cancer and for relating to other social actors and institutions (e.g., breast cancer organisations).

Despite efforts to recruit participants from diverse cultural backgrounds, a limitation of the study is that most participants were middle-class, Australian born and of European descent. Future studies could extend the current study to ensure that visual and discursive representations of metastatic breast cancer continue to be inclusive and expansive. A strength

of this study was the longitudinal approach in which participants were interviewed up to three times across a 12-month period, which permitted rich insights about the interwoven temporal, affective and relational aspects of living with incurable cancer.

Conclusion

This article has demonstrated how ‘living-with’ metastatic disease affected women’s social bonds in a way that speaks to many of the silent cultural assumptions and normative expectations of idealised patienthood and triumphant survivorship. Our findings have policy and practice implications, particularly in thinking about how to provide support in contexts of incurability. As survival rates continue to improve and as many more people will be living with metastatic cancer, how to support women to live well is an increasingly urgent question (Lewis et al. 2016). This article highlights the importance of focusing policy and research attention on identifying new ways of supporting women with metastatic breast cancer, and those around them, to negotiate flexible social bonds, ensuring women feel secure and connected. Here, breast cancer organisations can also play an important role in how they construct their rhetoric (sometimes designed to pull on the heart strings to raise research funds, sometimes to support and inform affected women) to be more inclusive of the diverse experiences and voices of women with metastatic cancer. Moreover, greater attention to the distinct support needs of people with metastatic cancer and how they differ from other cancer sufferers/survivors is vital. This includes breast cancer organisations considering how to deliver supports that are specific to metastatic breast cancer, for example through bespoke support groups and other avenues for enhancing beneficial peer support.

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Table 1: Participant characteristics (n=38)

Characteristic	Number (%)
Age (years)*	
<40	1 (3)
40-49	3 (8)
50-59	20 (53)
60-69	12 (32)
≥70	2 (5)
Time since metastatic diagnosis (years)*	
≤2	14 (37)
3-5	10 (26)
6-10	7 (18)
>10	7 (18)
Number of completed interviews	
1	3 (8)
2	4 (11)
3	31 (82)
Metastatic sites*	
Bone only	10 (26)
Visceral only	11 (29)
Bone and visceral	17 (45)

*at first interview

Table 2: Conceptualisation of social bonds

Name of bond	Definition
Threatened bond	Social bond in which a relationship is strained due to misunderstanding, suppression or omission of experiences or feelings
Severed bond	Social bond in which a relationship has been ruptured due to unreconcilable misunderstanding, suppression or omission of experiences or feelings
Attuned bond	Social bond in which a relationship is based on shared identification
Flexible bond	Social bond in which a relationship is based on mutual understanding