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## **Cancer survivorship, mor(t)ality, and lifestyle discourses on cancer prevention**

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### **Introduction**

Despite ongoing controversy and debate, the view that lifestyle factors such as weight, diet and exercise increase cancer risk has become commonplace in the scientific literature (Block, Patterson and Subar 1992, Manson *et al.* 1995, Steinmetz and Potter 1996, Allison *et al.* 1999, Friedenreich 2001, Fontaine *et al.* 2003, Calle *et al.* 2003, Irwin 2008, Renehan *et al.* 2008, Wolin *et al.* 2009, Harriss *et al.* 2009a, Harriss *et al.* 2009b). In recent years, this conviction regarding the importance of weight, diet and exercise has extended to people who have been diagnosed with cancer and the need to encourage lifestyle modifications in cancer patients *after* the completion of primary treatment in order to enhance their overall and disease-free survival (Demark-Wahnefried *et al.* 2006; Irwin 2008; Irwin and Mayne 2008).

It is worth quoting at length from a recent article published in the *Journal of Clinical Oncology* that provides some sense of the general tenor of this discourse:

Until recently, there was a degree of optimism among oncologists and researchers because descriptive studies suggested that individuals improved their lifestyle behaviors after being diagnosed with cancer... [M]ore recent, robust research... reveals that there may be comparatively fewer lifestyle differences between individuals with or without a cancer history than previously thought, especially among long-term cancer survivors. In fact, in some survivor subgroups, the practice of healthful behaviors may even be worse. Thus, although adjusted analyses indicate that survivors may be somewhat more likely to meet physical activity guidelines, the majority are much like the population at large—a population marked by sedentary behavior; overweight or obesity; and suboptimal fruit, vegetable, and fiber consumptions, and high intakes of saturated fat (Demark-Wahnefried *et al.* 2006: 5126).

Despite the lack of evidence regarding the impact of such lifestyle modifications on disease-free survival, the article is judgemental in tone and disappointment is expressed at the lack of lifestyle changes in cancer survivors.

A number of Foucauldian theorists have highlighted the relationship between risk, governance and a new morality consistent with the project of neoliberal self-surveillance

(e.g. Castel 1991, Rose 1993, 1999, Lupton 1995, Petersen & Lupton 1997, Petersen 1997). Neo-liberal rationality emphasises the entrepreneurial individual who is called upon to enter into his or her own self-governance through processes of “endless self-examination, self-care and self improvement”, taking responsibility to protect him or herself from ‘risk’ (Petersen 1997: 194; see also Rose 1993, 1999). Contemporary public health and health promotion discourses are premised on this neo-liberal logic of privatised risk management (Petersen and Lupton 1997). In this framework, if risk behaviours cannot be modified through sheer personal will, this is seen to constitute a “failure of the self to take care of itself” (Greco 1993: 361). Based on this logic, cancer patients who do not undertake lifestyle changes after their diagnosis are doubly culpable. The cancer diagnosis embodies their failure to take care of themselves, and their unwillingness to modify risk behaviours to prevent disease recurrence or progression is further evidence of their failure to adhere to the rights and responsibilities of the contemporary subject/citizen (Petersen and Lupton 1997).

Operating alongside of these public health and health promotion discourses on cancer prevention and treatment exist an alternative set of discourses that also emphasise the importance of individual lifestyle in preventing and managing cancer: complementary and alternative medical (CAM) therapies. CAM encapsulates a diverse collection of approaches (including naturopathy, homeopathy, herbalism, aromatherapy, acupuncture, reiki, etc) that are characterised by a lack of integration into Western healthcare systems and tend to espouse models of care that incorporate physical and metaphysical elements (Broom and Tovey 2008). A substantial proportion of cancer patients utilise CAM therapies, which are seen to move beyond the abstracted and depersonalised logic of risk that characterises biomedical approaches to cancer treatment, restructuring health as a subjective and individualised process (Broom and Tovey 2007, 2008).

Yet, while the emancipatory potential of CAM therapies is readily apparent, by locating the individual at the centre of decision-making and action they may serve to inadvertently ascribe blame (Broom and Tovey 2008). In the words of Baer *et al.* (1998: 1499-1500) “the holistic health movement runs the risk of becoming a subtle moral crusade which equates specific lifestyles with moral failures and in essence depoliticizes the social origins of disease by blaming the victim”. Thus, although starting from the premise of individual empowerment rather than risk management, the focus on lifestyle in CAM modalities may similarly serve to blame cancer patients for their cancer.

Although such lifestyle discourses clearly have the potential to place the onus on cancer survivors to manage the risks of disease recurrence and progression, it is essential to empirically investigate the ways that members of the lay population respond to the clinical gaze, rather than representing them simply as docile bodies constrained by hegemonic discourses (Lupton 1997). Yet, to date, no available studies have explicitly set out to explore how cancer survivors respond to this emphasis on lifestyle that has become ubiquitous in discourses on cancer and cancer survivorship. However, a number of studies have reported a strong emphasis on the importance of diet and exercise amongst cancer survivors<sup>1</sup> (e.g., Stewart *et al.* 2001, Maskarinec *et al.* 2001, Sinding and

Gray 2005, Markovic et al. 2006, English *et al.* 2008, Nelson and Macias 2008) and the value patients place on these behaviours as a way of managing the disease.

This paper focuses on the ways that people with a history of cancer engage with these discourses that stress the importance of lifestyle factors (particularly excess body weight, a poor diet and a sedentary lifestyle) in contributing to cancer and their role in managing disease recurrence and/or progression. The constitutive dimensions of these discourses (Foucault 1980) are explored, along with the ways that they shape the subjectivities of women and men with a history of cancer: both those who are disease-free and those who are living with cancer as a chronic disease partially controlled through treatment.

### **The study**

The arguments presented here are based on data collected as part of a larger ethnographic study which sought to learn more about the lives of cancer survivors attending cancer support groups and how their experience of cancer survivorship might differ on the basis of factors such as gender, cultural background, cancer stage and cancer site. Cancer support groups present an invaluable 'natural' setting for learning about the experiences of cancer patients and previous ethnographic research conducted at such groups has provided insights into patients' understandings of cancer (Mathews 2000) and the treatments they receive (Bell 2009).

Nevertheless, it is important to recognise that cancer support groups represent a particular context for exploring the experiences of cancer patients. First, cancer support groups tend to have a predominantly white, middle-class and female composition (Mathews 2000, Docherty 2004, Gottlieb and Wachala 2007) and therefore provide an avenue for primarily exploring the experiences of this subset of patients. Second, cancer support groups (particularly those that are peer- rather than professionally-led) emerged in the context of the self-help movement (Gray et al. 1997) and tend to be comprised of participants attracted by its philosophy of personal development and self-empowerment. Finally, Mathews' (2000) ethnographic research on a breast cancer support group would suggest that support groups may solidify particular understandings of the cancer experience as certain stories are circulated and get taken up within the group. Thus, the accounts presented by group members potentially reflect collective understandings more than individual experiences with the disease.

Four cancer support groups located in Western Canada were included in the study: a prostate support group, a colorectal support group, a group for women with metastatic cancer, and a support group (in Cantonese) for Chinese cancer patients. The prostate group was peer-led and the remaining groups were professionally facilitated and located onsite at a cancer treatment agency. All the groups had a drop-in rather than closed format, and each allowed for open discussion amongst participants, although there was some variation in the ways group meetings were structured and how regularly they were held. With the exception of the Chinese cancer support group, the other groups consisted primarily of white participants.

Participant observation was conducted at all support group meetings held over an eight-month period between September 2007 and April 2008.<sup>2</sup> The author carried out fieldwork in the colorectal, prostate and metastatic groups and employed a Cantonese-speaking research assistant to carry out the fieldwork at the Chinese cancer support group. In group meetings, the researchers observed without participating unless asked a direct question. However, these venues provided numerous opportunities to converse and interact with group participants informally. More active involvement occurred in other events connected with the groups, such as social gatherings, steering committee meetings, retreats, cancer forums and fundraising events.

Over the course of the eight-month fieldwork period, interviews were also conducted with thirty group members. Participants in the groups were invited to take part in an interview after fieldwork had been underway for several months and relatively equal numbers of participants from each of the four groups (7-8 people) volunteered to talk one-on-one. In total, nineteen women and eleven men were interviewed: twenty-one of the participants were white, seven were Chinese, one was black and one was Hispanic. The age of participants ranged from 45-81, with the majority in their 50s.

Open-ended interview questions were asked inviting participants to tell their story of being diagnosed with and treated for cancer, how they came to the group and their overall views on the group. Interviews were primarily conducted in the author's office located on site at the cancer treatment agency or in participants' homes, depending on their stated preference. With the consent of the informants, written notes of all interviews were taken. Interviews lasted on average 1.5 hours. The author conducted interviews with the metastatic, prostate and colorectal group members, and all were recorded and transcribed. The research assistant conducted interviews with the Chinese group members in Cantonese; only four (of seven) interviews were recorded, in keeping with the stated preferences of interviewees.

Qualitative data analysis software was used in the initial stages of analysis to facilitate coding and management of the data. Field note and interview data were coded using ethnographic coding processes (Emerson, Fretz and Shaw 1995), involving open coding to identify any and all ideas and themes in the material and focused coding as the fieldwork progressed, whereby the transcripts and field notes were subjected to a line-by-line scrutiny on the basis of topics that had emerged as of particular interest. Thus, as is typical in ethnographic research, research questions and findings were driven by the fieldwork itself (Sanjek 2000, Kapferer 2007).

The material presented in this paper relates specifically to the ways that study participants engaged with prevailing discourses on lifestyle and cancer risk. This was not an initial area of focus in the study, but as fieldwork progressed it became apparent that such lifestyle discourses (especially relating to diet and exercise) had a substantial impact on participants' experiences of cancer survivorship – their lives after the completion of primary treatment. Participants regularly raised these topics unsolicited in interviews and diet and exercise were a prominent feature of support group discussions.<sup>3</sup> Thus, the pertinent data generated in the context of the larger study has been extracted and analysed

using ethnographic content analysis techniques (Altheide 1987). It is this data that forms the basis of this paper.

### **Lifestyle ‘risk’ factors and the causes of cancer**

Participants engaged with lifestyle discourses on cancer prevention in complex ways that evidenced an underlying awareness of purported risk factors such as weight, diet and exercise, if not a wholesale acceptance of them. The following exchange in the support group for women with metastatic cancer represents a fairly typical interaction around the possible causes of cancer:

Michelle, a first-timer to the group, notes that she doesn’t understand why she got cancer because she has never smoked – aside from trying it once or twice when she was young. She then admits that she used to drink ‘inappropriately’ but she hasn’t touched alcohol for a very long time and she also eats healthily. Michelle concludes that they [scientists] really don’t know what causes cancer, despite the fact that people are constantly told that it [cancer] relates to diet, etc and continues, ‘I think it’s probably mostly environmental’. Cheryl adds that ‘just getting out of bed’ carries a cancer risk. Sandra volunteers that in her own case she thinks that it [the cause of her cancer] was genetics but admits that it may also be due to the fact that she was overweight. Daphne expresses surprise at this [Sandra is on palliative chemotherapy and has lost a considerable amount of weight since her diagnosis with metastatic cancer] and Sandra responds, ‘oh, you should have seen me, I was a real porker!’ She then looks down at her stomach and sighs that she is still overweight – pinching her gut with her fingers to demonstrate her point.

This exchange revealed a variety of opinions on the causes of cancer – most of them external (e.g. environmental factors, just getting out of bed) or uncontrollable (e.g. genetics). Although the possible role of weight in contributing to cancer was raised in a number of groups, such conversations invariably led to stories of being as “fit as a bull” and “incredibly healthy” prior to cancer, being vegetarian or “eating fish seven days a week”, yet ending up with cancer anyway.

These views are congruent with those found in previous studies of understandings of cancer aetiology in working class communities (e.g. Pill and Stott 1982, Balshem 1991), where participants emphasised the role of chance and other uncontrollable factors such as pollutants and genetics in the genesis of the disease. Participants’ views on cancer aetiology also echo those found in other studies of cancer survivors (e.g. Stewart *et al.* 2001, Manderson *et al.* 2005) where uncontrollable factors such as stress, environment, genetics and chance were highlighted over lifestyle factors such as weight and diet.

Many interviewees expressed a similar sense of ambivalence about the potential role of lifestyle factors in causing cancer. For example, the following exchange occurred with Michael, a black 55-year-old prostate cancer survivor:

KB: Do you speculate about what caused the cancer in the first place, and if you have speculated about that what are some of the...?

Michael: I would—I would think it's genetic, is a big part of it. But you know... I believe a lot of that stuff that they pump into our meat, you know, whether it's cattle or chicken or whatever it may be, growth hormones and whatever else they put into these things, that are getting into our bodies and playing with ourselves. And I feel that's where a lot of the cancers are stemming from. So is that how I got it? I don't know. I've always been fairly active, fairly fit for the most part. Eating healthy? I don't know, probably I'm average, I could do better, of course. But I think it's more genetics, that's my gut feeling.

A white 55-year-old colon cancer survivor, Jane, was more prepared to accept the possibility that diet and a sedentary lifestyle had a role to play in her cancer, although she similarly highlighted genetic inheritance:

KB: So I mean do you speculate now about what might have caused the cancer? Is that something that you think about...?

Jane: My dad's family was full of cancer, and I did phone an aunt by marriage... and I asked about my grandmother, because she had died in '48, before my parents even met. So I said 'Well, what kind of cancer did she have?' And she said, 'Well, it was stomach.' But I'm thinking it could have been bowel, but you know in polite conversation in the late 40's you wouldn't mention bowels... Well I think, you know, and I was afraid my sister who is, like, so athletic and eats properly and all that, would have said something to me... I had a very sedentary, almost sedentary, lifestyle. Because I worked so much, I didn't eat properly. So I mean I would tell you that but I wouldn't admit it to anybody else.

However, Jane went on to contextualise her lifestyle in terms of the stress<sup>4</sup> she had experienced in attempting to juggle work with the demands placed upon her as the sole caregiver for a parent in declining health, which she felt contributed greatly to the cancer. Manderson *et al.* (2005) documented a similar phenomenon in their study of views of cancer aetiology amongst gynaecological cancer survivors. Only two women in the study cited nutrition as a possible cause of their cancer, but both linked poor nutrition with environmental stressors such as financial hardship and the physical vulnerability caused by being 'run down'. As Manderson *et al.* (2005: 327) note, this allowed women to deny responsibility for cancer through their own behaviour – a concern that was also clearly evident in Jane's response. Jane highlighted her fears about receiving judgment, fears that presumably fuelled her admission that she would not admit the potential impact of her sedentary lifestyle and inadequate diet to anyone else.

Other participants also expressed an awareness of the possibility of being made to feel responsible for getting cancer – and nutritional discourses were singled out as producing a particular sense of culpability. For example, in a prostate group steering committee meeting, the following exchange about the following month's invited speaker, a nutritionist, was recorded in field notes:

Bob mentions that he saw the nutritionist speak at a conference and how interesting her talk was – he shows the others a summary of a global report on nutrition she [the nutritionist] has given him. John says that he doesn't like these sorts of reports because they make people feel guilty for getting cancer. Sam then jokes that they probably shouldn't be raffling off wine at every meeting to raise money, because alcohol is bad for you. Paul corrects him, noting in a serious tone that red wine is actually very good for you.

Peta, a 45-year-old woman with metastatic breast cancer, voiced similar views. In the context of a discussion regarding whether she would be interested in having a guest speaker come along to the group, she noted:

I like the idea of it [a guest speaker], yeah. But, you know, on the other hand I don't want someone sort of preachy coming in, you know what I mean? 'Oh you have', you know, 'this kind of an attitude and you can beat this – go out and buy my book!' So nothing like that. So, you know, in a sense a lot of the topics kind of talk down to us, and, you know, oh, nutrition or something. It's as if, yeah right, it's our fault, you know?

Such comments demonstrate an overt recognition amongst study participants of the potential for nutritional discourses to blame people with cancer for their condition because of the implication that individuals have a *choice* in whether they get cancer or not.<sup>5</sup> As Jane noted, the disease may be taken as evidence that people have been unable to regulate their own lifestyle.

### **Taking up lifestyle discourses on cancer**

Interestingly, although participants expressed considerable ambivalence about the potential role of lifestyle factors in contributing to their cancer, many highlighted the importance of healthy eating and exercise in managing the risk of cancer recurrence and/or disease progression. This belief was strikingly uniform across participants, regardless of cancer site, prognosis, gender or ethnicity. However, there were gender differences in which of these components (healthy eating or exercise) participants stressed, with women generally emphasising healthy eating and men focusing on exercise.

Women's preoccupation with diet was evident in a variety of contexts. For example, during a colorectal support group meeting a white 49-year-old female survivor, Sally, talked of the importance of nutrition:

Sally says that she has tried to book an appointment with a nutritionist, but because she is now okay [i.e. post-treatment and disease-free] she has not been able to get in. However, she says that she has been learning that eating healthily is key [to staving off a cancer recurrence].

Sally's comments echoed sentiments women in other support groups expressed about the need for 'good' nutrition. For example, despite having metastatic breast cancer, being on

a low income and with no access to a car, Susanna (a white 66-year-old woman) went to considerable lengths to ensure that she ate ‘healthily’:

Susanna: I also met with the nutritionist... So she’s put me on to things like, you know, eat your vegetables, eat your grains, eat your greens. So little by little I’ve been sort of turning it around.

KB: Right. In terms of what you’re—in terms of what you’re eating, then?

Susanna: Yeah, the nutritional part of it. So getting up in the morning and having three or four pieces of fruit or making my porridge now a couple of times a week. You know, choosing fish... I like to buy fruits and vegetables. I like to buy all my stuff and I usually go to the market about two or three times. I can take a bus right across town and go to, it’s not X [an expensive organic food chain], what’s the other one?—Y [Another expensive organic chain].

Several studies of cancer survivors (e.g. Stewart *et al.* 2001, Maskarinec *et al.* 2001, English *et al.* 2008, Nelson and Macias 2008) have observed the importance of nutrition and diet to this population, and the ways in which ‘healthy’ (especially organic) food is seen as a path to good health and healing. However, as Nelson and Macias (2008) point out, for women on low income, there is considerable expense connected with purchasing healthy foods, particularly organic products.

Participants in the Chinese cancer support group also highlighted the importance of diet in preventing disease progression – although these views were at least partially located in culturally-specific concerns about cancer-causing foods. Indeed, many participants raised the conflict between Chinese dietary practices and the nutritional guidelines and dietary advice they received from the cancer treatment agency and this was a source of considerable distress amongst group members (see Bell, Lee and Ristovski-Slijepcevic 2009). As Nelson and Macias (2008) point out, women of colour often experience particular difficulties in achieving dietary guidelines as the recommended diet is primarily white food that is often expensive and unsuited to their tastes. Thus, such women are left in a situation where they are convinced of the need to maintain a healthy diet in order to minimise the risk of recurrence, but the ‘healthy’ diets presented to them are either unaffordable, unpalatable, or both (Nelson and Macias 2008).

Unlike women, men generally emphasised the importance of exercise over diet.<sup>6</sup> This tendency echoes broader gender differences in preferred methods of weight control highlighted in previous research (e.g. Saltonstall 1993, Bell and McNaughton 2007). While body weight is a concern for many men, dieting is culturally constructed as a feminine activity and the most acceptable forms of weight management are masculine pursuits such as weight lifting and exercise (see Bell and McNaughton 2007). For example, one regular in the prostate cancer support group, Amit, a middle-aged South Asian man, would regularly raise the importance of exercise in informal conversation, emphasising the value of regular exercise and reiterating that he tried to go to the gym each day.<sup>7</sup> This was also a prominent theme in individual interviews with men. Thus, according to Jack, a white 56-year-old prostate cancer survivor:

I was very proactive in my own treatment, and as such I started going to a gym, and because I had read about exercise being beneficial. And I kept that up actually throughout all the diagnosis and right up to the treatment – and soon thereafter. I kept my membership going, and right afterwards I was back at the gym doing really, really easy things, you know, that fit within the mandate of what I should be allowed to do. And I still keep that up.

Paul, a 54-year-old white colon cancer survivor, also highlighted the importance of exercise in his interview:

KB: Is fatigue something you're suffering from?

Paul: No, I'm not. I feel good, I feel really good. I go to the gym every day. I feel great, I really do.

KB: Did you go to the gym a lot before? I mean has this been...?

Paul: Yeah, but now I go more.

KB: Okay, so this has really changed.

Paul: You know, when I'm there I think I'm fighting the cancer. Like, I have to do this. I think I'm totally addicted.

KB: To going to the gym?

Paul: Yeah.

Although men and women tended to engage with different elements of lifestyle discourses on cancer prevention, common to the accounts of both was an emphasis on exercise and/or diet as a way of gaining some individual *control* over the possibility of cancer recurrence or progression. Thus, Paul saw himself as fighting the cancer through exercise and Jack saw it as a way of being proactive. Similarly, Sally viewed diet as key to staving off a cancer recurrence.

The general acceptance of the value of diet and exercise in protecting against disease recurrence and progression might appear to contradict the widespread ambivalence about the role of such factors in causing cancer in the first place. However, participants' acceptance of lifestyle discourses in this context must be located within the experience of cancer survivorship itself. People with a history of cancer who have been designated "cancer-free" live with a disease that is considered in remission but not cured – a space that Frank (1991, 1995) has termed the "remission society". The experience of cancer survivorship therefore entails profound ambiguity: is remission partial or permanent? "When does long-term survival become apparent 'cure'? ...The condition thus raises problems of meaning" (Comaroff and Maguire 1981: 117). People with metastatic cancer—many of whom are increasingly living with cancer as a chronic disease at least partially controlled through treatment—experience even more acute concerns about the need to keep their cancer in stasis and avert disease progression.

The high prevalence of CAM use amongst both survivors who are cancer-free and patients living with metastatic disease can be largely explained by the fact that these alternative therapies depart from biomedical notions of 'cured', 'healthy' or 'disease-free' and focus instead on *wellbeing* (Broom and Tovey 2007). In their research on CAM use amongst cancer patients, Broom and Tovey (2007) found that a significant proportion

of patients had ambivalent feelings towards statistics and probabilities on cure because such statistics could not provide concrete knowledge about how they *as individuals* would respond to treatment. CAM therapies were particularly appealing to patients with more advanced disease, allowing them to critically assess prognostic data and maintain hope in the face of poor survival odds. Thus, by ‘going along’ with lifestyle guidelines, participants are not merely passive or docile recipients of hegemonic discourse; rather, they “...could be seen as engaging in practices [and projects] of the self that they consider are vital to their own well-being...” (Lupton 1997: 105).

While these practices or techniques of the self are irreducible to the techniques of domination (Foucault 1980), “it may be that the latter are presupposed by, or are conditions for the possible existence of, the former” (Burchell 1993: 269). Thus, the stress many cancer patients place on diet and exercise can lead to a situation in which the body is experienced as at imminent threat of recurrence or disease progression if its inputs (foods) and outputs (exercise) are not constantly monitored. Several participants – including some with advanced cancer – expressed this need for absolute vigilance around diet and exercise. In her interview Lori, a white 64-year-old woman with advanced leukaemia, highlighted the need to watch her weight and avoid certain foods, noting that she had to tell herself: “Lori, you can’t have that!” when confronted with sweets. Mrs Wong, a Chinese 63-year-old breast cancer survivor, expressed a similar vigilance around diet:

My attitude is that the cancer agency has given me many booklets about what I should eat at each stage that will be helpful to me.... I do not have boiled chicken soup at all. Instead, I would eat more yoghurt, milk that will give me more protein... My focus is on recovery. *Everything I do is for recovery and not to eat anything that will be worse for my health* [author’s emphasis].

Importantly, some men expressed a parallel need for vigilance around exercise; for example, Paul, the 54-year-old colon cancer survivor emphasised that going to the gym was something he had to do in order to fight the cancer. This need for vigilance around diet, exercise and body weight invariably led to a sense of guilt when participants experienced a lapse in will power or failed to live up to what they saw as a healthy lifestyle.<sup>8</sup>

This sense of vigilance around food and the forms of self-surveillance and disciplining it engendered, have been noted in previous studies. As one woman in Sinding and Gray’s study of breast cancer survivors (2005: 152) commented, “Every time I put something in my mouth I’m aware and vigilant—if I have (fast food), I need lots of salads after. I keep a little tally of good things, bad things...” Similarly, in Broom and Tovey’s (2008) study of cancer patients’ experiences of CAM therapeutics, they found that such therapeutic regimes often created a form of governance of the self whereby patients “...felt bad if they slept in, ‘missed an enema’ or had negative thoughts” (p. 1655). As Broom and Tovey (2008) note, motivations for healing in this context relied on retaining a sense of ‘unwellness’ or pathology.

### **Resisting lifestyle discourses**

Although men and women engaged with these lifestyle discourses on cancer risk to varying degrees, there was also evidence of resistance to these forms of ‘scientific’ knowledge – resistance that often stemmed from the experience of living with the disease. In the case of women with metastatic cancer, the experience of incurable cancer created counter-discourses to the lifestyle frame and its emphasis on individual responsibility to manage disease progression. Thus, one recurring motif in the metastatic group was the need to appreciate life and live it to the fullest, and the freedom the disease gave participants to let go of prescriptions and proscriptions about how they should think, look and behave. Many women in the group would say things like: “Instead of asking myself ‘should I take this cake or that?’ I think, ‘I’ll take both – what am I waiting for?’” Interestingly, while these counter-narratives challenge the individualisation of health and self-responsibility evident in alternative medical discourses on cancer survivorship, they simultaneously share central features with the alternative and self-help movements in terms of the focus on creative self-transformation and the emphasis on cancer as a psychological “makeover opportunity” (Ehrenreich 2001).<sup>9</sup>

Another source of resistance to lifestyle discourses on cancer risk was the experience of being constantly bombarded with contradictory information about the causes of the disease – of living in a world in which just getting out of bed carries a cancer risk. As support group participants noted on many occasions,<sup>10</sup> everything is seen to cause cancer.<sup>11</sup> Many participants readily questioned the veracity of the dietary information they received – particularly the mixed messages regarding what food was beneficial and what should be avoided. One such exchange with a man in the prostate cancer support group was recorded in field notes as follows:

At the beginning of the meeting I take a seat next to an elderly black man with a lilting Caribbean accent. I ask how long he has been coming to the group and he notes that he has been coming along for over three years. He first heard about the group from a nurse [at a local hospital] after he was diagnosed and started coming to the group before he had treatment. I ask if he was at the previous meeting where a nutritionist was invited as a guest speaker and ask what he thought of the lecture. He tells me that the problem with these nutrition lectures is that each person contradicts the information from the time before. Our conversation is cut short by the beginning of the day’s lecture on nutraceuticals... After the lecture has finished we talk a little more about the content of this month’s lecture. He reiterates that there seem to be a lot of mixed messages – one person says you shouldn’t take/eat something and then another person says you should.

Peter, a white 81-year-old prostate cancer survivor who had recently experienced a recurrence, expressed similar views. The following exchange occurred when I asked him what previous lectures he had attended at group meetings:

Peter: Um (laughing), I think one was diet.

KB: Right. Why are you laughing?

Peter: Ah, because people are always on the diets.

KB: Yes. And is that something in your own life that you are concerned about, in terms of—[the cancer]?

Peter: No, no. I'd like to lose weight, but diet is—a lot of the stuff is unproven, I think. And I'm not cynical but, you know, you read about so many things that you wonder, you know? The biggest thing that I always discuss is butter. Butter and margarine. You know, I get up and I go out and buy a block of butter, because I like butter.

KB: Yeah, I do too.

Peter: You know, and then people say 'Well, you should have at least had margarine.' And there's no proof that margarine is any good. This is the whole thing.

Conversations often had a similar tone in metastatic group meetings, where women would question received wisdom about what was supposed to be 'good' for them. For example, on one occasion:

The facilitator asks who wants coffee – someone then jokes that she hopes the coffee is 'decaffeinated'. Brenda complains that she doesn't understand why everyone thinks coffee is bad – sometimes when she drinks coffee people tell her off about it, but she 'loves it' and could 'never give it up!' Cheryl then asks about whether there is any sugar and the facilitator jokes about it being another 'bad' food.

In the groups, it was common for participants to joke about and mock the dietary advice they received. For example, at a Christmas social gathering for the metastatic support group women were talking about overindulgence at Christmas and someone mentioned the "80/20 rule". When another woman asked what this meant the speaker explained that "as long as 80% of the food is healthy, the other 20% can be whatever you want". Women in the group then started joking about whether the "50/50 rule" still counted, everyone laughing uproariously at this discussion. Similarly, in the prostate group, the bottle of wine raffled off at each meeting was the source of a running joke about whether they might be promoting an 'unhealthy' substance.

### **Conclusion and implications**

This paper has explored the ways in which women and men with a history of cancer engage with lifestyle discourses regarding the relationship between cancer and 'risk' factors such as weight, diet and exercise. Research findings show that study participants evidence a complex engagement with such discourses "marked by varying degrees and combinations of critique, acceptance, discomfort, compromise and caution" (Nelson and Macias 2008: 29).

Overall, there is no doubt that discourses regarding the relationship between lifestyle and cancer risk and management have penetrated the consciousness of cancer survivors to a substantial degree. Men and women in the study were all clearly aware of these purported risk factors, which were invariably raised (if ultimately dismissed) in participants' reflections on the possible causes of their cancer. Importantly, many participants were aware of the underlying moralism of such discourses and their individualising and stigmatising potential. Several participants explicitly highlighted the

sense of guilt, blame and judgement such discourses produced. Thus, instead of ‘buying into’ lifestyle discourses emphasising individual risk factors within their control, men and women tended to highlight external and uncontrollable factors as the likely source of their cancer, such as genetics, stress, and the environment.

However, while tending to reject lifestyle factors as the cause of their cancer, there was what can be characterised as an “ambivalent engagement” (Nelson and Macias 2008: 20) with these discourses amongst many participants. To varying degrees they endorsed the idea that weight, diet and exercise impact disease recurrence and progression – although such views were gendered, with women focusing on diet and men focusing on exercise as the path to a healthier body. Understanding and experiencing the body in these terms created in some participants a need for vigilance around bodily inputs and outputs in order to stave off the disease. Yet, for others, such views were tempered by alternative sources of knowledge about the shortness of life and the need to enjoy it to the fullest. There was also a degree of scepticism borne of living in a world where anything and everything can be seen to cause cancer and foods and activities that are deemed ‘good’ today might be labelled ‘bad’ tomorrow.

It could be argued that whether diet and exercise impact survival or not, it is still useful to encourage cancer survivors to monitor their weight, improve their diet and increase their exercise levels. Indeed, some existing evidence suggests that such lifestyle interventions have functional and quality-of-life benefits for cancer survivors<sup>12</sup> in helping to relieve treatment side effects (see Demark-Wahnefried *et al.* 2006). However, ultimately, there is still a great deal we do not know about cancer – a disease that “seems to call into question the effectiveness of current scientific knowledge itself” (Comaroff and Maguire 1981: 116). Yet, to date, public health *and* complementary and alternative medical discourses tend to rely on an individualistic model regarding the causes of cancer and potential external factors (such as environmental pollutants) remain understudied (Balshem 1991, Baer *et al.* 1998, Ehrenreich 2001). While lifestyle factors may play a role in cancer aetiology, the relationship is clearly a complex one. Thus, to over-emphasise these factors runs the risk of perpetuating some rather old ideas about cancer as a personal moral failing: whereas previously it was deemed a failing of the mind and the inadequacies of an inhibited, repressed personality (Sontag 1990), it now becomes a failing of the body and the individual will to control it.

## Notes

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1 These studies have primarily been conducted with breast cancer survivors, who tend to be overrepresented in the literature on cancer survivorship.

- 2 This period included 14 metastatic group meetings, 8 prostate group meetings, 8 colorectal group meetings and 7 Chinese group meetings.
- 3 During the fieldwork period, two of the groups also invited a guest speaker to discuss the topic of nutrition (the prostate support group and the Chinese support group).
- 4 This view of stress as a key cause of cancer was common to many participants, showing the ongoing currency of popular cultural theories relating to the relationship between stress and disease.
- 5 The form of cancer most clearly associated with a ‘failure of the self to take care of itself’ is lung cancer. People with lung cancer are often highly stigmatised (Chapple, Ziebland and McPherson 2004) because of the view that ‘they brought it upon themselves’ and there is evidence that many health care professionals discriminate against smokers and people with smoking-related diseases such as lung cancer and COPD (Canadian Lung Association 2005).
- 6 These gender differences appeared to crosscut cancer stage and site.
- 7 For prostate cancer survivors exercise may be particularly important as a means through which they can reassert their manhood in the face of cancer treatments that undermine hegemonic masculinity in other respects – especially in connection with erectile function (see Wall and Kristjanson 2005, Oliffe 2007). It is worth noting that virtually every man I met in the prostate cancer support group made a point of introducing exercise into the conversation almost immediately and highlighting how regularly he exercised and how quickly after treatment he started.
- 8 It can also lead to a sense of personal failure in the context of a cancer recurrence in a way similar to a belief in the power of positive thinking (Stewart *et al.* 2001, Doan and Gray 1992).
- 9 I am indebted to one of the anonymous reviewers for this insight.
- 10 Often these discussions occurred in the context of someone raising a recent news item suggesting a link between yet another apparently innocuous item (e.g. plastic water bottles) and cancer.
- 11 Balshem (1991) also notes the prominence of this motif in her study of understandings of cancer in a working class community and the ways it was used as a source of resistance to scientific discourse on cancer prevention.
- 12 Although these studies often assume that “the relationships between body weight, health, food and physical activity are so finely calibrated and so well understood that just a tweak here and a tweak there can produce measurable health improvements”, when in reality these relationships remain poorly understood (Gard and Wright 2005: 128).

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