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**Cancer Diagnosis as Discursive Capture:
Phenomenological Repercussions of being Positioned within Dominant
Constructions of Cancer**

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Abstract

This paper is concerned with the phenomenological repercussions of being positioned within widely available social constructions of cancer. Being diagnosed with cancer can constitute a challenge because it requires the person to make sense of the diagnosis and to find meaning in their changed circumstances. From a social constructionist point of view, such meaning is made out of discursive resources which are available within one's culture. This paper reviews some of the dominant discourses surrounding cancer which are available within English-speaking Western Industrialised cultures. It maps out the discursive positions available to those diagnosed with cancer and it traces some of their implications for how cancer can be experienced and how it may be lived with. The paper reflects on the relationship between discourse and phenomenology, arguing that in order to fully appreciate the experience of a cancer diagnosis we need to be aware of the discursive field within which it takes place.

Introduction

In an earlier paper (Willig, 2009) I reflected on the process of meaning-making during the process of being diagnosed with cancer. In this earlier paper I described my own experience of the process of attempting to construct and maintain a serviceable narrative that made sense of what was happening to me in the midst of emotional turmoil and uncertainty. I reflected on the experience of being thrown into a new and unsettling discursive universe and the consequences of this for my experience of myself and my relationships with other people. One of the key points I made in the paper was that upon being diagnosed with cancer I quickly realised that not all available ways of making sense of my experience were helpful to me. I also noticed that during a time when I was still searching for meaning in my experience, other people's comments on my situation (and the meanings around cancer which they invoked) could be extremely unsettling for me. It felt as though I had to work hard to resist and hold at bay proffered meanings which, to me, seemed unhelpful or even destructive.

In this present paper, I build upon, but also move beyond, my own experience. I aim to map out the discursive positions available to those diagnosed with cancer and to trace some of their implications for how cancer can be experienced and lived with. As such, this paper is concerned with the social and psychological consequences of being positioned within some of the dominant discourses associated with cancer diagnosis in

contemporary English speaking Western Industrialised cultures such as those found in the United Kingdom, the USA, Australia and New Zealand.

The Role of Diagnosis

Jutel (2009: 278) argues that “[D]iagnosis is (...) a powerful social tool, with unique features and impacts which deserve their own specific analysis”. She observes that research into the social processes associated with diagnosis has explored the place of diagnosis in the institution of medicine, the social framing of disease definitions, the means by which diagnosis confers authority on medicine, and how that authority is challenged. In this paper, I am concerned with the effects of a medical diagnosis beyond the clinic. I focus on how a medical diagnosis positions the patient in relation to ‘healthy’ others in society rather than in relation to medical professionals which appears to be a more common focus in social research in this area (see Blaxter, 2009 and Jutel, 2009 for reviews of such literature). I examine the phenomenological repercussions of such positions for those who find themselves in them. I am also concerned with the narrative struggle (that is, the struggle over what constitutes a legitimate narrative), both internal and external, which takes place once a person has been thrown into the discursive space available to those diagnosed with cancer within a particular socio-cultural context.

Whilst this paper is particularly concerned with the more problematic aspects of the discursive construction of being diagnosed with cancer, I do acknowledge that there are

also positive (social and psychological) consequences of diagnosis including a sense of validation of a complaint once it has been recognised as a legitimate medical condition (eg. Lillrank, 2003, with regard to chronic back pain) and access to a collective identity and a reduction in social isolation (eg. Chiong, 2001; both of these cited in Jutel, 2009). This is particularly the case for those diagnosed with “rare, unfamiliar or ‘poorly understood’ disorders” for whom access to and identification with support groups can be very helpful (Fleischman, 1999: 18).

The Role of Discourse

The way we talk about something is important because people situate personal experiences within a social and discursive context. Discourse constructs the objects and subjects of which it speaks; discourses may therefore be defined as “sets of statements that construct objects and an array of subject positions” (Parker, 1994: 245). Part of the discursive context within which people experience being diagnosed with cancer includes increasingly frequent media coverage of cancer ‘survivor stories’ of celebrities and ordinary people (see Wray, Marcovic & Manderson, 2007:3 for examples), widely available public health/health promotion materials concerned with cancer prevention and lifestyle advice (Lupton, 1995) as well as popularizations of scientific articles in the media (eg. Williams Camus, 2009).

As early as 1977, in *Illness as Metaphor*, Susan Sontag (1991) explored the various subject positions contained within widely used cancer metaphors (such as cancer as a “demonic enemy” which must be fought; p. 59) and their implications for those who are captured by them. She observed that “(...) it is hardly possible to take up one’s residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped” (1991:3). Sontag argued that giving a disease moral meaning is a punitive process which positions those who are diagnosed with the disease as culpable, as tainted, as shamed. More recently, Stacey (1997) has presented a comprehensive account of how cancer is perceived, experienced and theorised in contemporary society. Unlike Sontag, who excluded biomedical discourse from her critical reading, Stacey’s analysis includes an examination of alternative/complementary therapy, self-help as well as biomedical discourses. Through an exploration of her own experience of being diagnosed with and treated for cancer, Stacey demonstrates how various constructions of cancer contained within these discourses positioned her and shaped her experiences including her sense of self, demonstrating, as she (1997: 28) puts it “(...) some of the ways in which a person with cancer is subject to, if not bombarded with, powerful and contradictory discourses about the nature of their illness” and the “confusion and panic” that can result from this. In her book, Stacey (1997) offers a commentary on the meanings attributed to cancer by the various health and cancer cultures she encountered during her illness. These include i) the idea that cancer symbolises something (such as the cancer patient’s inner weakness and self-destructiveness), ii) the assumption that cancer is unspeakable and monstrous, iii) the belief that a positive attitude makes recovery more likely and that a healthy body requires a ‘healthy mind’, iv) the belief that the patient can contribute to the success of

their treatment by visualising the destruction of the disease, v) the expectation that the patient ought to be(come) an expert on themselves and the new imperatives of the care of the self that result from this, vi) the idea that ultimate responsibility for one's health lies with oneself, and finally, vii) the construction of death as unacceptable and a failure which ought to be avoided (see Stacey, 1997: 25-28 for a summary).

In what follows, I identify a number of dominant discursive constructions of meaning around cancer which those who have been diagnosed with cancer will almost certainly encounter and which are therefore likely to mediate the ways in which they are able to make sense of their experiences. My discussion draws on my own experience of being diagnosed with cancer (Willig, 2009), a range of recently published research papers as well as earlier work by Sontag (1991) and Stacey (1997). The phenomenological implications of being captured and positioned by these constructions will be explored and their social-psychological consequences will be considered.

Discursive Constructions of Cancer and Its Meanings

The Cultural Imperative to 'Think Positively'

My own experience of being diagnosed with cancer made me acutely aware of the presence of something like a cultural imperative to 'think positively'. Thinking positively means demonstrating faith in the belief that things will turn out well and that every problem can be solved. In relation to a cancer diagnosis, it also seems to mean that death

as a possible outcome is not to be acknowledged or talked about. I (Willig, 2009: 185) soon realised that to acknowledge death as a possible outcome was constructed as a morbid preoccupation, as “something unhealthy and illegitimate (or impossible), at least while death is a mere possibility rather than a certainty”. Similar observations have been made by other authors. In her recent book aptly entitled ‘Smile or Die’, Ehrenreich (2009: 26) argues that “[E]xhortations to think positively - to see the glass half full, even when it lies shattered on the floor (...)” pervade North American culture including ‘breast cancer culture’ (Ehrenreich, 2009: 45). She describes how her own experience of being diagnosed with and treated for breast cancer made her realise that “[P]ositive thinking seems to be mandatory in the breast cancer world, to the point where unhappiness requires a kind of apology”. Ehrenreich draws on a wide range of material posted on internet-based cancer support group websites as well as other relevant publications (eg. first-person accounts, advice leaflets, books about how to live with cancer) in order to demonstrate the pervasiveness of a cultural imperative to think positively about cancer. Within these texts, cancer is constructed as a ‘wake-up call’ to rethink one’s life, an opportunity to make a fresh start and to live a better, healthier life as a result. Within this context, Ehrenreich (2009: 27-9) cites descriptions of cancer as “a gift” and “the best thing that ever happened”. In a much earlier review of research into the social expectations encountered by cancer patients, Wortman and Dunkel-Schetter (1979: 134) already identified “[T]he assumption that the patient should avoid thinking or talking about the negative aspects of his or her situation, and attempt to remain as cheerful and optimistic as possible”.

Recent research into the social and emotional consequences of word choice (Mosher & Danoff-Burg, 2009) demonstrates how the cultural imperative to think positively about cancer is reflected in interpretations of linguistic classifications of individuals with cancer. Mosher and Dandoff-Burg (2009) found that across two studies which compared reactions to the use of the terms ‘cancer survivor’ and ‘cancer patient’, a large sample of undergraduate students attributed consistently more positive qualities to someone described as a ‘cancer survivor’ (as opposed to ‘cancer patient’) and they expressed more positive attitudes towards them. In the second study, participants also expressed a significantly greater willingness to interact with “cancer survivors” than with “cancer patients”. This suggests that a ‘positive’ stance towards having cancer, one which focuses upon survival and active living (‘survivor’) as opposed to one which foregrounds passivity and suffering (‘patient’), is socially desirable and rewarded. Interestingly, Mosher and Dandoff-Burg (2009) cite three recent studies which have found that people who are receiving health care themselves actually prefer the label ‘patient’ to alternatives such as ‘survivor’ or ‘consumer’ (see Deber et al., 2005; Lloyd, King, Bassett, Sandland & Savige, 2001; Nair, 1998).

One way in which the cultural imperative to take a ‘positive’ stance towards having cancer manifests itself is through a construction of cancer as war and the widespread use of military metaphors which instruct patients to ‘fight their illness’ (see Ross, 1989; Lupton, 1994). Stacey (1997: 172) describes how visualisation as a form of self-healing advocated by alternative approaches to cancer treatment involves the mobilisation of mental images of “fighting and destruction” whereby “the cells of the immune system

and the cancer cells make up opposing armies which will fight until death". Stacey (1997) notes that, somewhat ironically, these metaphorical images are derived from the militaristic immune system discourse prevalent in mainstream medicine and based upon the medical model.

Williams Camus (2009) presents a comprehensive analysis of the use of metaphor in popularizations of scientific articles on cancer in the English press. 'Cancer is War' was found to be the most frequently used metaphor, a finding which is supported by earlier research (eg. Van Rijn-van Togerren, 1997; Clarke, 1992; Seale, 2001). This construction is also something that Sontag's (1991) early polemic against the use of metaphor in cancer discourse identified and challenged. 'Cancer as War' constructs cancer as an enemy who must be fought at all costs and by any means necessary. It instructs patients to not give up the fight, positioning the body as a battlefield upon which the struggle between life and death is fought. Collateral damage (to the body, to the patient) is to be expected and must be accepted as an inevitable part of this process. Soldierly bravery and stoic acceptance together with an optimistic attitude and a belief in one's ability to 'win the battle' are required and expected. The desirability of 'positive thinking' is implied by the construction of cancer as war since it is assumed that if the patient shows enough determination to win and fights hard enough they can win the war. 'Not giving up' is valued more highly than any other stance within this context. Obituaries and other references to cancer-related deaths in the media demonstrate this by almost inevitably constructing the death as a casualty of a 'battle with cancer'. It seems as though it is not acceptable to simply die of cancer- one must first 'do battle' with it ¹.

¹ Within this context it is interesting to observe that in the opening paragraph of a newspaper article about the death of the actor Lynn Redgrave (The Guardian, Tuesday 4th May 2010, p. 3) the actor is described as

Another way in which ‘positive thinking’ manifests itself in cancer discourse is through the construction of cancer as a problem to be solved. Here, cancer is constructed as a challenge to the human intellect and to science which can potentially be tackled.

Williams Camus’ (2009) analysis of popularizations of scientific articles in the British press identified the repeated use of metaphorical themes such as ‘cancer is a puzzle’, ‘cancer is a riddle’, ‘cancer is a tangle’ and ‘cancer is an enigma in a detective story’ (Williams Camus, 2009: 480-3). These metaphors invoke an optimistic narrative which implies that progress is continuously being made and that discovering a cure for cancer is only a matter of time because every problem has a solution- it just needs to be found. As with the other constructions of cancer which mobilise a discourse of ‘positive thinking’, the construction of cancer as a problem to be solved means that staying with the experience of cancer and attempting to relate to it *as it is* are not an option. All of these constructions imply that cancer can and must not be accepted- it must be fought, solved or otherwise changed into something else, something more benevolent and something which removes its association with death.

Cancer as a Moral Concern

My own experience of other people’s reactions to my cancer diagnosis included an encounter with the construction of cancer as a moral concern (Willig, 2009). It seemed as though my diagnosis called for an explanation which positioned me at the centre of the

having “died aged 67 after a lengthy battle with cancer” which is followed, in paragraph three, by a citation of the family’s own official statement which read “Our beloved mother Lynn Rachel passed away peacefully after a seven-year journey with breast cancer”. It seems that the construction of ‘cancer as war’ is so ubiquitous that even the family’s own alternative construction of ‘cancer as a journey’ has not deterred the author of the article from invoking the compulsory “battle”.

action. Once identified as a cancer patient, my lifestyle seemed to become a legitimate subject of interest and I was asked questions about what I might have been doing to bring cancer into my life (eg. was I still smoking ? Had I been sunbathing too much ? Was I eating a balanced diet ?). Both Stacey (1997) and Ehrenreich (2009) observe similar attributions of responsibility contained within contemporary cancer discourse. Stacey (1997) reviews both relevant literature and her own experience of a range of alternative treatment approaches to cancer, noting that cancer is frequently constructed as a sign of degeneration, corruption and decay, indicative of the cancer patient's inner weakness and self-destructiveness. She argues that a contemporary "model of cancer as a disease 'occasioned' by the self" (p. 175) is the product of a combination of current beliefs about the aetiology of cancer (eg. that it is 'home grown', the product of spontaneous cell growth; the role of lifestyle and behavioural factors), popular mind/body metaphors associated with complementary medicine and 'New Age' thinking (eg. the idea that a healthy body is the external manifestation of a healthy mind) and militarised immune system discourse (eg. the image of the immune system as the body's army trained to fight foreign invasion which, in the case of cancer, has failed to recognise an internal enemy bent on self-destruction). The result is a construction of cancer as the patient's own creation and, therefore, ultimately their responsibility. One implication of this is the expectation that the cancer patient ought to accept this responsibility and declare ownership of "their" cancer. Within this context, references to cancer as a "wake-up call" are common (Willig, 2009; Ehrenreich, 2009), implying that preceding their diagnosis the cancer patient had been lax and inattentive regarding their self-care and that the cancer diagnosis had been necessary to awaken them from their complacent state of disregard

for their own health. High levels of vigilance and responsible behaviour are expected of the patient once a diagnosis of cancer has been made. Stacey (1997) draws a link between this moral positioning of the cancer patient and a new form of moral citizenship associated with what has been described as a new 'imperative of health' (Lupton, 1994) and a remoralisation of health in the late twentieth century (Gillick, 1984).

The Body as Object

My own experience of being diagnosed with cancer changed my relationship with my body which seemed to lose its status of being the self's ally to becoming its enemy. I described how my self "(...) began to feel like a hostage, at the mercy of a damaged container that may self-destruct and destroy my 'self' along with it" (Willig, 2009: 186). I experienced my (healthy) self as very much separate from my (diseased) body, and yet this separation was a fragile state of affairs which required much mental effort to sustain. Any encounters with constructions of the body as an independent entity with its own inner workings and mechanisms beyond the control of the self felt unsettling and threatening to me. I noticed that conversations about 'my body' and what was happening within 'it' made me feel strangely excluded and invisible, as though my body was taking over and my sense of self was (at risk of being) lost. It has been proposed that modern medical technologies which produce 'objective' representations of the body and which form the basis of diagnostic and treatment-related decisions, contribute to a preoccupation with the 'disease' (e. the identification of objective disease markers in the body) at the expense of the 'illness' (ie. the experiential dimension of ill health), reflecting and enhancing the disease orientation of medical language (see McCullough,

1989) . As a result, it is argued, “[T]echnological representations hide the selves embedded in human bodies, reinforcing the already alienating effect of hospital medicine” (Blaxter, 2009: 763). However, Blaxter (2009) suggests that the way in which such representations are recorded, interpreted and used (and the extent to which the patient is actively involved in this process) can moderate the degree of alienation. In her analysis of popularizations of scientific articles about cancer in the British press Williams Camus (2009: 473-5) identifies the widespread use of the construction of ‘cancer as machine’ which she links with the wider ‘body as machine’ metaphor whereby the body is constructed as being made up of parts with different functions which together allow the machine to function and ‘do its job’. ‘Cancer as a machine’ constructs cancer as a faulty mechanism which interferes with the smooth running of the body-machine. Williams Camus (2009:475) notes that this metaphor has been criticised for dehumanising the patient (eg. Stibbe, 1998; Coulehan, 2003; Fleischman, 2001) by excluding the experiential dimension of ill health.

Phenomenological Repercussions

Having sketched the discursive context within which those diagnosed with cancer are positioned, I want to go on to explore some of the social and psychological repercussions of this positioning. I want to move from the discursive to the phenomenological by making links between the discursive positions available to cancer patients and the experiential world(s) they may give rise to. The second half of this paper is, therefore,

concerned with experience: what is it like to be captured by dominant constructions of cancer and how may available subject positions shape the experience of being diagnosed with cancer ?

The discursive constructions identified above (the cultural imperative to ‘think positively’; cancer as a moral concern; the body as object) each foreground particular dimensions of meaning around which the experience of being diagnosed with cancer is organised. At the same time, they obscure or exclude others. This has implications for how a cancer diagnosis can be experienced and for what is seen (and experienced) as a ‘legitimate’ way of being a cancer patient. The following discussion explores some of the repercussions of the discursive constructions identified earlier for cancer patients’ ability to engage with suffering and mortality, for their experience of managing responsibility and for coping with alienation.

Engaging with suffering and mortality

The cultural imperative to ‘think positively’ foregrounds the patient’s responsibility to do all s/he can to regain health. It privileges a ‘restitution narrative’ (Frank, 1995) which constructs illness as a temporary interruption of the ‘normal’ state of being which is health. This means that acceptance (of illness, of suffering, of mortality) is not a legitimate way of finding meaning in a cancer diagnosis. The cultural imperative to ‘think positively’ constructs acceptance as ‘giving up’ and it taints the patient who chooses to accept their fate with the undesirable qualities of the deserting soldier, the one who surrenders, who lacks the moral courage to continue to fight the enemy. Staying with the experience of suffering and finding meaning within it, without attempting to make it go

away, is not a socially acceptable option. Experientially, this also means that coming to terms with mortality, “making peace with death”, as van Deurzen (1998: 12) puts it, is not encouraged and the patient who wishes to engage with their mortality will struggle to find a social space within which to do so. It also means that those whose cancer is clearly terminal find themselves excluded from the dominant narrative (restitution) at a time when emotional and social support is most needed. Finding meaning in their experience is likely to become a major challenge when the dominant narrative fails to make sense. At the same time, the cultural imperative to ‘think positively’ implies that a ‘negative’ outcome (such as death) is simply too terrifying to contemplate and that, therefore, it must be denied until the last possible moment. This is likely to increase the fear of death and it means that those who have reached the point where ‘positive thinking’ does not make sense anymore may find themselves unprepared and very much alone in finally confronting their mortality.

Managing responsibility

The cultural imperative to ‘think positively’ instructs those diagnosed with cancer to fight back and not give up. It positions the patient as active agent in the cancer drama and it attributes ultimate responsibility to the patient for the outcome of their battle where, morally speaking, not giving up is as highly valued as winning (as demonstrated by the obligatory reference to the ‘battle with cancer’ in obituaries and media reports of cancer-related deaths). Similarly, the construction of ‘cancer as a moral concern’ also positions the patient at the centre of events. This time, responsibility is attributed retrospectively, by scrutinizing the patient’s psychological make-up and lifestyle in the search for

aetiological factors. Foregrounding the patient's individual responsibility for 'their cancer' leads to what Ehrenreich (2009: 43) describes as 'victim-blaming' which "(...) can weigh on a cancer patient like a second disease". In addition, it can also divert attention from the role of external factors (such as environmental pollution or lack of speedy access to screening and medical treatments) in cancer aetiology and mortality. As Stacey (1997: 175) points out the construction of cancer as "a disease 'occasioned' by the self" implicates the very core of the cancer patient's identity, their character and personality, in the aetiology of the disease. This means that it can be difficult for the patient to separate 'self' and 'disease' leading to a sense of overall corruption and inadequacy. The malaise then transcends the medical frame of reference and begins to require moral adjustments, the first of which is the acceptance of responsibility for the disease, followed by the promise to heed the 'wake-up call' and to change one's ways. Experientially, this means that for the cancer patient to gain social approval, s/he needs to reject his/her former self and to engage in a process of moral renewal. Refusal to do this may mean losing social support and missing out on empathy.

Coping with alienation

Constructions of 'the body as object', akin to a piece of equipment or a mechanical contraption, conceive of the body as an entity entirely separate from the self. This is not the body as the locus of subjective experience or the embodiment of personhood. Rather 'the body as object' is the non-human, material part of the Cartesian body-mind duality. Within the context of cancer diagnosis, a construction of 'the body as object' positions the self as being trapped within, and therefore at the mercy of, the diseased body, of what

I have described as a “damaged container” (Willig, 2009:186). By conceptually separating the body from the self, the self loses control over the body and this becomes a frightening prospect once the body itself is diseased. This is particularly poignant within the context of cancer which, as Stacey (1997: 79) points out, “(...) is widely understood as a disease of uncontrolled cell growth”. An alienated body out of control constitutes a direct threat to the integrity and survival of the self. Experientially, this means that when the body becomes the object (of the medical gaze, of conversations about disease progression, of technological representations) the patient’s self is under siege and at risk of being lost. Since within the dualistic model the patient’s humanity is located within the self, a preoccupation with the diseased body and its faulty mechanisms can also engender a sense of being dehumanised, that is to say, a sense of not being related to as a person. Martial cancer metaphors (discussed earlier within the context of the cultural imperative to ‘think positively’) which construct cancer as a formidable enemy which has invaded and colonised the body and which must be fought by any means necessary also draw on constructions of ‘the body as object’. In this case, the body, again dehumanised, is constructed as the battleground upon which the war against cancer must be fought and where collateral damage is an inevitability. The cancer patient as a person is separated from their body which itself becomes the enemy since the cancer resides within the body’s own cells. Chemotherapy, its toxic effects and the suffering this occasions for the patient illustrates the ambiguous status of the patient’s body within the ‘war on cancer’. Experientially, this means that the patient’s relationship with their own body is likely to be ambivalent as it is not obvious to what extent the body is an ally and to what extent it is the enemy (see also Williams Camus, 2009, for a discussion of the social psychological

consequences of martial cancer metaphors). In addition, the patient's physical needs as a person (eg. for physical closeness to others, for physical intimacy) can easily disappear from view when the body becomes a battlefield and the patient may feel that a desire for physical comfort and human contact is inappropriate and needs to be suppressed, particularly during treatment.

Taken together, an exploration of the phenomenological implications of being positioned within dominant discursive constructions of cancer suggests that engaging with suffering and mortality, managing responsibility and coping with alienation may constitute particular challenges for those diagnosed with cancer. It is interesting to note that in an early paper on the interpersonal environment of cancer patients, Wortman and Dunkel-Schetter (1979) identified a number of barriers to receiving validation and support from others which echo some of the observations made in this paper. They note that there is a large body of evidence which demonstrates that cancer patients encounter considerable difficulties in their relations with others as a result of their diagnosis. Wortman and Dunkel-Schetter (1979) develop a model of the interpersonal environment of cancer patients which attempts to trace the social processes by which cancer patients receive responses from others that are “inconsistent, confusing and ultimately destructive” (p.124). In particular, Wortman and Dunkel-Schetter (1979) draw attention to widespread beliefs about the need to display optimism and cheerfulness when in the presence of a cancer patient. This attitude is difficult to sustain in the face of suffering and distress and, they argue, that it can lead to

behaviours such as physical avoidance of the patient, avoidance of open communication, and a range of discrepant, contradictory behaviours. In addition, Wortman and Dunkel-Schetter (1979) identify the tendency to believe in a 'just world' (Lerner, 1970) where people get what they deserve, leading to individual attributions of responsibility for contracting cancer. In this way, the authors argue, those close to the cancer patient can protect themselves from the fear of contracting cancer themselves as this would constitute 'undeserved suffering', leading to a further distancing from the cancer patient and their experience of living with cancer.

The Struggle for Meaning

Although much of what has been discussed in this paper so far has been concerned with the experience of being positioned within dominant cancer discourses in general (rather than the process of being diagnosed with cancer in particular), I want to argue that these general positionings and their phenomenological and social repercussions are intimately bound up with, and indeed dependent upon, the social process of diagnosis. Diagnosis marks the moment when a set of phenomena (such as an array of signs and/or symptoms, a series of test results, episodes of ill health) are transformed into disease categories. Such categories constitute medical interpretations of experiential and social phenomena, and they usually offer both aetiological as well as prognostic meanings which organise the illness experience including treatment options and procedures. A diagnosis also carries

moral connotations particularly in relation to aetiology (eg. to what extent is the patient responsible for ‘bringing on’ the condition ?) and contagion (eg. is the patient responsible for containing the disease ?) Diagnostic categories, once applied to a person, position them as a ‘patient’ and as a ‘sufferer’ of the pathological condition that has been diagnosed. Diagnosis, therefore, marks the moment when the individual is inserted into the discursive field associated with the diagnosis they have received. Fleischman (1999: 10) draws attention to the “transformative power” which medical language has over patients whereby,

“[I]f a person is told ‘you have cancer’ (or any life-threatening disease) *these words* irrevocably alter that person’s consciousness, view of the future, relationship with family and friends, and so on” (italics in original).

Fleischman (1999) illustrates the significance of language and the choice of words within this context by contrasting the various alternative diagnostic labels which have been used to refer to the set of symptoms which constitute the rare blood disorder Fleischman herself has been diagnosed with. These labels include ‘refractory anaemia’, ‘preleukaemic disorder’ and (the currently preferred) ‘myelodysplastic syndromes’, amongst others. Fleischman notes that each of these labels constructs the haematological pathology in a different way, foregrounding different aspects of the condition, with the reference to ‘pre-leukaemia’ constructing a particularly threatening version of it. Diagnosis initiates the struggle for meaning, both internally (ie. What does it mean to me to have been diagnosed with cancer ? Who am I now and how will I live ?) and externally

(ie. How do others see me now that I am ‘a cancer patient’ ? How will I be positioned in relation to (healthy) others and what role can I play socially, now that I have been diagnosed with cancer ?). It also provides some of the discursive resources with which meaning can be made, and it limits and constrains the meanings which can be constructed by the individual. As Fleischman (1999: 13) puts it,

“For the afflicted individual, illness becomes a trope for new attitudes toward the self; it also influences perceptions of that self by others (...) if the diagnosis is *refractory anemia* the impact on all concerned is dramatically different from a diagnosis of *preleukemia*” (italics in original).

The struggle for meaning after a cancer diagnosis is challenging and it can be painful. In what follows, I reflect on the experience of being inserted into cancer discourse, its emotional quality and the importance of the socio-cultural and historical context within which it takes place.

The experience of being constructed by and positioned within cancer discourse

Both Stacey (1997) and Ehrenreich (2009) powerfully evoke the sense of vulnerability and mortification that accompanies the experience of being constructed by and positioned within dominant cancer discourses. Both authors communicate a sense of loss of control over the story that they can tell about themselves and a struggle to regain control over the narrative which will, eventually, make sense of their experience of being diagnosed with

cancer. Similarly, in my own account of the struggle for meaning during the process of cancer diagnosis (Willig, 2009: 182) I observed that,

“(…) I also realised that, in this situation of uncertainty, when feeling anxious and vulnerable, other people’s comments and observations (and the discourses of health and illness which they evoked) had a great impact on me. At times, it felt like I had to actively ‘defend myself’ against proffered meanings, which, to me, seemed unhelpful or even destructive”.

Likewise, in her reflections on her experience of being diagnosed with a rare and life-threatening blood disorder, Fleischman (1999: 7) observes,

“When the body is seriously out of kilter, particularly if the condition is likely to endure, your sensitivity to the nuances of words used to describe it is inevitably heightened. You become critically aware of the subtle ways in which lexical choices define you as a person”.

It seems that at a time when narrative wreckage threatens, when an existing storyline ceases to make sense of our current experience, we are particularly vulnerable to what Frank (1995: 6) has described as ‘narrative surrender’. Being diagnosed with cancer requires adjustments and modifications to one’s sense of self – for example, by incorporating a stronger awareness of mortality, of physical and/or psychological vulnerability or by changing one’s relationship with one’s body. Finding bearable

meaning in a cancer diagnosis and coming to terms with its implications for one's sense of self is not easy, particularly whilst powerful messages from loved ones and the wider society about what it means to be a 'cancer patient' are received at the same time.

In their interview study of 19 female breast cancer patients' experiences of the impact of an altered appearance during chemotherapy treatment, Harcourt and Frith (2008) identified two key themes within the data: i) anxiety that chemotherapy would render them identifiable as a 'person-with-cancer', and ii) problematic interactions with others. In particular, the loss of hair (including any attempts to disguise this, for example, by wearing a headscarf or a wig) was feared as it was seen to impart information about their disease status to others and, therefore, to lead to them being identifiable as a 'person-with-cancer'. Such an identification, in turn, led to a loss of control over how to define oneself and over how one was treated by others (eg. with unwanted attention, with sympathy or pity when they just wanted to 'blend in', with unwanted advice or unsolicited opinions about the causes of cancer). In other words, participants feared and experienced a loss of control over who they were and who they could be within a social context. For some participants, their attempts to regain control led them to avoid social interactions, thus echoing Wortman and Dunkel-Schetter's (1979) concerns about cancer patients' social withdrawal. Being identifiable as a 'person-with-cancer' was experienced as stigmatising and the visible signs of being treated for cancer exposed them to invasions of privacy (cf. Goffman, 1963), a phenomenon which was also identified in a study of the experiences of women with gynaecological cancer (Wray, Markovic and Maderson, 2007) ².

² Phenomenologically speaking, the experience of stigma and the consequent invasions of privacy can engender a sense of shame. Being seen (for example, as marked by the outward signs of cancer treatment)

The (social, historical, cultural) context in which meaning is made

It is important to acknowledge that the struggle for meaning after cancer diagnosis always takes place within a very specific socio-historical and cultural context. Such a context makes certain discourses more or less available, it foregrounds particular constructions of meaning and it obscures others. Fleischman (1999) draws attention to role of language in this and she reminds us that languages differ with regard to the lexical and grammatical options they make available in order to construct meaning around the experience of health and illness. For example, languages differ in the way in which they construct the relationship between a person and their illness whereby some languages allow for the possibility of an existential identification with one's health problem (eg. by saying 'I am a diabetic') whereas others do not, instead preferring a subject-object split between person and disease (eg. by using the construction 'I have diabetes'). In addition, in most languages and cultures, the body and its various constitutive parts take on symbolic meanings, acting as metaphors for mental and physical states and conditions (eg. in English, 'blood' signifies transmission of qualities or characteristics via the notion of lineage as well as of contagion) which are activated when a body part or organ is diagnosed with a pathology. This means that, as Fleischman (1999:21) puts it,

and categorised (in this case, as a cancer patient) can lead to a feeling of being trapped within a spoilt identity which foregrounds undesirable and morally dubious personal attributes (such as lack of courage and self-destructiveness, as discussed in an earlier section of this paper). In his discussion of 'being-for-others', the social dimension of his phenomenological ontology, Sartre (2003) identifies the moment when we experience being seen by another person as the moment when we become aware of ourselves as an object within the other's world. This moment is characterised by "the shock which seizes me when I apprehend the Other's look" and the realisation that "(...) the Other is the hidden death of my possibilities" (Sartre, 2003: 288). This is because the other's look expresses the fact that it is him/her, not me, who gives meaning to the object which I constitute in his/her world. Shame ensues when we experience ourselves as the object which the other is looking at and judging. Through 'the look' we are trapped in the other's world and have to live with the consequences. Sartre (2003: 286) implicitly invokes the role of discourse in this process when he observes that "[W]e are dealing here with my being as it is *written* in and by the Other's freedom".

“When you contract a disease, you contact with it the world of that disease, including all its affective and culture-specific meanings, which are frequently symbolic or metaphorical”.

Other authors, such as Ehrenreich (2009) and Klawiter (2004), have drawn attention to the role of the wider socio-cultural and ideological contexts which mediate the experiences of those diagnosed with cancer by making available particular socially and culturally specific disease regimes. Ehrenreich (2009) describes a US American ideology of ‘positive thinking’ fuelled and sustained by underlying economic interests. Such an ideology foregrounds individual responsibility (for health, for success, for employment, for access to opportunities) and elides the influence of corporate forces and the political economy. Such an ideology constructs breast cancer as an opportunity to demonstrate one’s superior personal qualities including optimism, resourcefulness and resilience but does not allow for expressions of anger, sadness or hopelessness, and it does not encourage political action to tackle the environmental causes of increasing rates of breast cancer in the USA.

Klawiter (2004) traces changes over time in the availability of illness experiences as they are shaped by social movements. In her analysis of one woman’s narrative of being diagnosed with breast cancer twice, first in 1979 and again in 1997, she demonstrates how changes in breast cancer regimes (including institutionalised practices, authoritative discourses, social relations, collective identities, emotional vocabularies, visual images, public policies and regulatory actions), facilitated by movements of breast cancer

activism in the 1990s in the San Francisco Bay Area, made available two very different illness experiences at these two points in time. Whilst the woman's experience in 1979 was characterised by the sovereign power of physicians, isolation and disempowerment of patients, gender- and hetero-normative assumptions about female embodiment, the invisibility of women with breast cancer and the lack of a group identity, her experience in 1997 offered a very different illness experience involving a more egalitarian relationship between patients and physicians, involvement of a wide variety of support staff, expansion of access to medical information, participation in medical decision-making, new specialist social services and resources, a growing visibility of women with breast cancer, new collective identities and the presence of a multi-stranded breast cancer movement. Whilst the woman's initial experience of breast cancer was "relentlessly individualised" and characterised by "stigma, isolation and invisibility" (Klawiter, 2004: 865-6), the second regime of breast cancer had reframed the disease allowing her to experience herself as a participating, visible, supported and respected cancer patient. Klawiter (2004: 866) concludes that localised, historically specific 'regimes of disease' shape illness experiences and that an understanding of such regimes of practices "enhances our ability to historicise and contextualise the structural shaping of illness experience".

What is striking about the analysis of cancer discourse presented in this paper is the relentless and unforgiving individualism which characterises the positionings made available to those diagnosed with cancer within the various constructions of cancer identified here. From the assumption that the individual's commitment to his/her 'battle against cancer' can make the difference between life and death, to the notion of cancer as

a disease occasioned by the self in the first place, attributions of individual responsibility for cancer abound. This reflects the foregrounding of the individual citizen and their rights and responsibilities (as opposed to the role of collectivities and the political economy) characteristic of a worldview shaped by capitalist principles in general and, more recently, by neo-liberal ideologies in particular (eg. Stephenson and Papadopoulos, 2006). There is also evidence of a preoccupation with control and the assumption that gaining control over events by shaping them and, ideally, directing them is always desirable. By contrast, accepting what is happening and staying with an experience (rather than trying to control or change it) is not presented as a legitimate option. Such an orientation reflects Western values, in particular those associated with scientific progress and human control of the natural environment. It is particularly interesting to note that what may be described as ‘alternative’ cancer treatments associated with ‘New Age’ thinking construct the person with cancer in ways that are just as strongly shaped by Western capitalist ideologies as are the more mainstream, medicalised approaches (see Stacey, 1997).

Conclusion

In this paper I have attempted to integrate discursive and phenomenological perspectives by exploring the implications of discursive constructions of cancer and the positionings made available by them for the lived experience of those diagnosed with cancer. Drawing on my own experience as well as recently published analyses of cancer discourse, I have

mapped out some of the dominant constructions of cancer and I have explored the ways in which these foreground, and indeed privilege, particular versions of the cancer experience. The cultural imperative to ‘think positively’, moral connotations of cancer as a disease occasioned by the self (cf. Stacey, 1997), and a construction of the body as not fully human and distinct from the self emerged as the central discursive structures identified in contemporary cancer discourse . I have reflected on what it may be like to be diagnosed with cancer within this discursive field, proposing that the positionings on offer would make it difficult to engage with suffering and mortality, that they would place the burden of responsibility for their cancer and its progress (or otherwise) upon the individual, and that there would be a sense of alienation (from one’s body and from other people). I have also drawn attention to the relationship between available cancer discourses and practices (‘cancer regimes’, as Klawiter, 2004, puts it) and the specific socio-historical and cultural context within which a person experiences a cancer diagnosis. A pervasive individualism and the imperative to take (and maintain) control over events were identified as important ingredients of cancer discourse, demonstrating a link between cancer discourse and the wider social-political and ideological context within which it is produced.

From a methodological point of view, my argument has been that an understanding of the discursive context within which people experience a cancer diagnosis can enhance our understanding of the experience itself (see also Willig, 2000; Willig, in press). The publication of personal narratives of illness experiences including critical reflection on the social and discursive contexts within which these experiences have taken place (eg. Blaxter, 2009; Ehrenreich, 2009; Frank, 1991, 1995; Fleischman, 1999; Stacey, 1997) has

greatly contributed to our understanding of how illness experience is mediated. Such accounts demonstrate just how powerful the (social and psychological) effects of being positioned within dominant illness discourses can be and how strongly they influence our relations with other people and, indeed, with ourselves. Diagnosis, as the moment when we are thrown into a new discursive field (within which we will have to survive, socially and psychologically, from then on) is an essential part of the process of being captured by dominant constructions (of cancer, of illness). As such, personal accounts of coming to terms with being positioned within cancer discourse contribute significantly to the development of a sociology of diagnosis. Further research into the interplay between discourse and experience in relation to illness will expand this field and help us to develop both the theory and practice of diagnosis.

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