

# PSA testing: Molecular technologies and men's experience of prostate cancer survivorship

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## Abstract

Although the value of the PSA (prostate-specific antigen) test as a cancer-screening instrument remains hotly contested, over the past two decades its usage has become commonplace. While most men diagnosed with prostate cancer will die with rather than of the disease, widespread PSA screening has led to an attendant increase in cancer diagnoses and the usage of aggressive treatments to 'combat' it. Despite the central (if controversial) role that PSA now plays in the diagnosis of prostate cancer and monitoring for recurrence, few studies have set out to explore its role in men's experiences of the disease. Drawing on ethnographic fieldwork at a prostate cancer support group in western Canada, we seek to delineate the meanings the PSA test holds for prostate cancer survivors. For many men in the study, their PSA levels were seen to provide an objective indicator of the presence or absence of cancer, with important implications for their subjective experience of cancer diagnosis and survivorship.

## Introduction

Prostate cancer is the most commonly diagnosed cancer in North American men (CCS/NCIC 2007, SEER 2009) and reports indicate that the incidence of the disease has risen dramatically in recent years. However, these changes in incidence must be contextualised in relation to the emergence of the prostate specific antigen (PSA) test in 1988 as the key means of screening for the disease. Via the PSA test and other cancer screening technologies that have accompanied the rise of surveillance medicine (Armstrong 1995), physicians have penetrated the "silence of the organs" to discover within them the signs, seeds, portents, predispositions of pathology to come" (Rose 2001: 12). The widespread use of such screening technologies has thus had a number of important consequences: serving to exponentially increase diagnoses of cancer (particularly early-stage cancer) in asymptomatic populations and leading, in part, to an expanding population of long-term cancer 'survivors'.

While cancer-screening tools such as mammography and pap smears have generally been lauded as invaluable in the 'fight' against cancer, the introduction of PSA testing has not been without controversy. First, PSA levels are elevated in both benign diseases of the prostate (e.g. benign prostatic hyperplasia) and in malignancies (Lin et al.

2008), thus requiring further tests such as biopsy of the prostate to confirm a cancer diagnosis. This limitation of the PSA test is exacerbated by the unique aetiology of prostate cancer – which remains poorly understood. Unlike other malignancies, the majority of prostate cancers are not likely to progress so as to result in premature death and or serious illness. These 'silent' cancers have been variously termed 'latent', 'incidental', 'indolent' or 'dormant' (Green, Kazanjian and Gallagher 2000). Indeed, almost 90% of new cases are localised to the prostate gland, suggesting that most men will die with, rather than of, the disease (Potosky *et al.* 2000).

Although modifications to the PSA test have been proposed that may help to improve its predictive value, such as measuring PSA velocity (D'Amico *et al.* 2004) and density (Aslan *et al.* 2005), it is not presently possible to predict which prostate cancers will progress dangerously and which will remain indolent.<sup>1</sup> Consequently, available evidence does not support the conclusion that screening asymptomatic men with PSA leads to fewer deaths or an improvement in the quality of life for those with prostate cancer (Lin *et al.* 2008, Andriole *et al.* 2009, Schroder *et al.* 2009).

As a result of these substantial limitations of PSA as a screening device, most national guidelines do not support the implementation of universal PSA screening programmes and recommend that men requesting it be informed of its limitations prior to being tested. However, despite this lack of endorsement, PSA testing has become commonplace over the past two decades, leading to an attendant increase in prostate cancer diagnoses – especially of low grade cancers. Commercial interests (e.g., surgeons and pathology laboratories) that benefit from an expanded disease category may be driving at least some of this diagnosis creep (Aronowitz 2009). However, a variety of factors appear to be responsible for the demand for PSA screening amongst men, including beliefs about the benefits of early cancer diagnosis (Chapple *et al.* 2002a).

The widespread demand for PSA screening must also be understood in relation to the rise of risk society (Beck 1992, Giddens 1999) and the distinctive relationship to health and the body it has engendered. As Giddens (1999: 4) notes, risk society brought with it manufactured risks associated with science and technology that “create as many uncertainties as they dispel”. This manufactured uncertainty intrudes directly into personal and social realms as people have to take a more active and “risk-infused orientation” towards their lives (Giddens 1999: 4). Indeed, privatised risk management is a fundamental *expectation* of citizens under the conditions of contemporary forms of neoliberal governance (Rose 1993, 1999, Lupton 1999, Petersen and Lupton 1997, Clark *et al.* 2003). As Petersen and Lupton (1994: 69) note: “ideal ‘healthy’ citizens have their children immunised according to state directives, participate in screening procedures such as cervical pap smears and blood cholesterol tests...”. Seen in this light, PSA tests entail another form of bodily monitoring and surveillance that men as ‘responsible’ citizens should adopt (Petersen and Lupton 1994: 87; Clark *et al.* 2003). Indeed, research suggests that a sense of responsibility does motivate men to undergo PSA screening (Chapple *et al.* 2002a).

Many asymptomatic men, when faced with abnormal PSA results and informed that they have prostate cancer, are prepared to undergo aggressive treatment in the hopes of ridding themselves of the disease.<sup>2</sup> A similar phenomenon is evident in the realm of breast cancer, where there has been a parallel growth in the use of aggressive treatments (including prophylactic mastectomy) for women diagnosed with in situ or non-invasive breast cancers via routine screening (Aronowitz 2009). Such responses are unsurprising when we consider the culturally loaded nature of the term cancer, its status as the most feared disease, and the emotionally and socially devastating nature of the diagnosis (see Sontag 1990). However, they also speak to the ways in which risk medicine has led to a converged experience of risk and disease, such that risk states have become virtually indistinguishable from disease states, both leading to intensive surveillance, aggressive intervention and subjective feelings of uncertainty, danger and loss of control (Aronowitz 2009, Armstrong 1995).

The two primary interventions available for men diagnosed with localised prostate cancer are radical prostatectomy or brachytherapy – a type of radiation therapy that involves the implantation of radioactive seeds in the prostate. Unlike other cancers where there is a clearly defined treatment trajectory, men are confronted with two different treatment options, both with reasonably equivalent long-term outcomes. However, considerable iatrogenic morbidity is associated with both forms of treatment (Steginga *et al.* 2001, Eton and Lepore 2002, Wall and Kristjanson 2005), including the risk of treatment-related death and treatment side effects such as erectile dysfunction and urinary incontinence that may be severe and life long. However, these side effects are not merely experienced as physical outcomes of treatments, but pose a substantial challenge to men's sense of masculinity (see Gray *et al.* 2002, Wall and Kristjanson 2005, Oliffe 2005). Therefore, there is a real danger that a large number of men who would otherwise live out their normal lifespan with asymptomatic prostate cancer will instead be burdened with the emotional and health impacts of a cancer diagnosis and treatment.

In light of these treatment side effects, a third viable treatment option known variously as 'conservative management', 'watchful waiting', and 'active surveillance' is also available for men diagnosed with low grade cancers. As the names suggest, this option involves monitoring men diagnosed with low risk prostate cancer for disease progression and only taking aggressive treatment measures in the context of such progression. However, few men avail themselves of this option.<sup>3</sup> For example, one large study found that only 8% of men diagnosed with prostate cancer chose watchful waiting as an initial treatment and these men tended to be significantly older than those who chose more aggressive treatment (Chapple *et al.* 2002b).

As a result of men's and healthcare professionals' preference for aggressive cancer treatment, the advent of PSA testing has dramatically altered the age profile of men who undergo prostatectomies and the median age for men treated from the disease has dropped substantially over the last 20 years (Khan *et al.* 2005). Moreover, since the beginning of the 'PSA era', there has been a huge increase in treatment for *localised* and *early-stage* disease, with radical prostatectomy rates increasing 2 to 4-fold for men in

their 50s and 60s between the late 1980s and the turn of the twenty-first century (Moul 2000).

Since the late 1990s health-professionals have been observing the effects of this diagnosis and localised treatment boom, and many men each year are now experiencing PSA-only disease recurrence (Moul 2000, Moul 2006). PSA recurrence is defined as an “isolated, detectable rising PSA level *without other clinical signs of disease*” (Pound and Partin 2000: 28; emphasis ours). Thus, while there is evidence that the PSA is the best method of predicting the likelihood of cancer recurrence after prostate cancer surgery (McCleod 2005, Moul 2006) “the questions that arise concern the definition of recurrence and what, if anything, needs to be done at a given point at the first discernable rise” (McLeod 2005: S29).

It is now increasingly recognised that biochemical ‘failure’ alone is not a justification *per se* to initiate treatment (McLeod 2005, Moul, Banez and Freedland 2007). As McLeod (2005) notes, “At the first time of detectability, a rise in PSA may be a harbinger of failure in some patients, but it is not necessarily equivalent to clinical failure of subsequent biochemical failure” (p. S31); “A decision to implement therapy, usually with some form of HT [hormone therapy], must be carefully weighted against net implications of how such therapy will deleteriously impact quality of life” (McLeod 2005: S30).

Despite these controversies, there has been little research into the experiences and understandings of PSA among men treated for prostate cancer and its ongoing role in and impact on their lives. Drawing on data from a larger ethnographic study of cancer support groups, this paper provides a preliminary exploration of the ways that members of a prostate cancer support group (PCSG) talk about the PSA test and their PSA levels. Through excerpts from both field notes and ethnographic interviews, we seek to delineate the meanings that the PSA test holds for prostate cancer survivors, and the impact it has on men’s *experience* of cancer and survivorship – their lives after the completion of primary cancer treatment.

### **Research Setting**

The setting was a peer-facilitated PCSG held in western Canada. As is typical in PCSGs, it looked rather different from the stereotypical cancer support group. According to Gray *et al.* (1996), PCSGs revolve around information rather than overt ‘support’. There is generally an effort to recruit as many people as possible to the group and guest speakers are the major focus of group meetings (Gray *et al.* 1996, Oliffe *et al.* 2008). The PCSG where fieldwork was conducted was no exception to this general pattern: meetings regularly drew at least 50 people and revolved around a presentation by a guest speaker – although a smaller cohort of men (10-15) generally stayed for an informal round-circle discussion after the formal meeting.

The group drew men at a variety of stages in the cancer trajectory, including those recently diagnosed with cancer who were still deciding on which treatment path to take, long-term cancer survivors, those who had experienced a recurrence, and, as is common in PCSGs (see Bottorff *et al.* 2008), a small number of female partners. Interestingly,

although cancer support groups tend to be dominated by white middle class cancer patients (Avis *et al.* 2008), this group was notable in regularly attracting a significant minority (at least 25%) of men from non-white ethnic backgrounds (including South Asians, North Asians and Afro-Caribbeans).

### **The study**

Bell conducted participant observation at monthly PCSG cancer support group meetings (N=8) held between October 2007-May 2008 and observational data were recorded as field notes during the group meetings. The group leader provided permission for the study on behalf of group members and Bell was formally introduced to the group prior to the initiation of fieldwork. For the benefit of newcomers to the group, she was reintroduced at monthly group meetings as a researcher interested in learning more about men's experiences of prostate cancer. Because of the large size of group meetings, the regular presence of women at the meetings and the fact that many audience members took notes during the guest speaker's presentation, the participant observation was unobtrusive and minimised the 'observer effect' that would likely be apparent in a smaller setting.

Aside from the participant observation at the support group meetings, in-depth, semi-structured interviews were conducted with seven group members. Participants in the group were invited to take part in an interview after fieldwork had been underway for several months and all seven men approached Bell expressing an interest in being interviewed – she had interacted with all men, to varying degrees, prior to their interview. On average, interviews lasted approximately 1.5 hours and with the consent of participants, all interviews were recorded and transcribed verbatim. Interviews covered basic questions about men's diagnosis with prostate cancer, their experience of cancer treatments, their lives after primary treatment, and their views on the support group itself.

The material presented in this paper relates specifically to the ways that study participants discussed PSA. This was not an initial area of focus in the study: men were not explicitly asked about their PSA levels or their views on the PSA test. However, as fieldwork progressed it became apparent that the PSA test played an important ongoing role in the lives of prostate cancer survivors in the group. As has been noted in previous studies (e.g. Chapple and Ziebland 2002, Oliffe and Thorne 2007, Oliffe 2009), men frequently referred to their PSA results in conversation within the group and often raised this topic unsolicited in individual interviews. Indeed, it often appeared to be a crucial reference point in discussing their *experience* of prostate cancer. 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.

### **'Seek and ye shall find': PSA and the diagnosis of prostate cancer**

Four of the seven men interviewed had their prostate cancer diagnosed through a routine PSA test. Two of the remaining three men had their prostate cancer diagnosed before PSA tests became widely available: one through a digital rectal exam (DRE) and the other through a routine biopsy following surgery for an enlarged prostate. The third man

was diagnosed more recently, but a DRE picked up his cancer – his PSA levels remained in the ‘normal’ range when his doctor palpated abnormalities in his prostate.

Of those men who had their cancer detected through a PSA test, all had early stage cancer, and generally a slight rise in PSA levels triggered a series of events culminating in a biopsy of the prostate and the cancer diagnosis:

George: Last year, [it] was still okay. Every three months or so I take PSA test before, but then in December, January—was it next month?—suddenly it was higher. It was higher and they said I should get a biopsy, because there’s some indication that there could be cancer down there. So [a] biopsy [was] made in May, beginning of May, and then the result was ‘yes’, it was cancer (white male, 60s, alternative therapy followed by radical prostatectomy, <1 year post diagnosis).

John: My doctor called me at work and said Hi John, it’s Dr X’ and I go ‘yes’. Your doctor doesn’t normally call you at work, and she goes ‘Oh well, your PSA has gone from 1.3 to 3.0. It’s nothing, don’t worry about it, but I want to see you. I want you to go to a urologist and talk to them about it.’ So that’s how this whole thing started (white male, 50s, radical prostatectomy, <6 months post diagnosis).

Several men provided detailed accounts of slight rises in PSA levels leading to aggressive PSA monitoring, followed by a subsequent biopsy (or biopsies) and cancer diagnosis. Richard, for example, had his first PSA test at 49 and at 2.6 he was told his reading was just above the ‘normal’ cut off for his age group (2.5). His doctor then sent him to see a specialist, beginning a two-year period wherein Richard had PSA tests every three to six months, each time registering tiny fluctuations in his PSA levels. As a black male with a family history of prostate cancer, Richard described this as a period of high anxiety, with each slight rise in his PSA levels triggering intense fears alleviated only after the results of painful biopsies. He was finally diagnosed with stage T1C cancer in 2004 in the following circumstances:

So now we must be 2004 and it comes back at 3.0. It had gone back up again. So I said, ‘Okay, now I guess we have to go through another biopsy.’ ...So I had that, and then the same thing again, three weeks later I’m to go back... and to get the results... So I go in there and he eventually comes in and says ‘Well, how are you doing?’ and I said ‘Good.’ And he says ‘Well, you have prostate cancer’ (black male, 50s, radiation, <3 years post diagnosis).

Kevin’s story was similar to Richard’s, although he demonstrated an awareness of the controversy surrounding the PSA test, noting “the original brochure from the Municipal Service Plan was somewhat discouraging, you know, for taking a PSA, because they... went down the path of saying that it wasn’t a very accurate test”. Nevertheless, he went ahead and requested a PSA test, and his initial test came back slightly high for his age

bracket (4.8 when he was told that the ‘normal’ range was about 3.5). This triggered a trip to a urologist, further PSA tests and his eventual diagnosis with stage T1B prostate cancer.<sup>4</sup> In Kevin’s words:

It [PSA levels] had kind of been up and down a teeny bit and when you put all those tests together, but to me, there wasn’t anything really significant. He [the urologist] felt that it was, the general trend was a slight rise... So anyways, after the higher PSA test, after he got basically the same results he said that that was enough PSA testing. He said that there was no point doing anything else and he wanted to do a biopsy... So anyways, the biopsy was pretty quick after that that I went in for...I had the biopsy at [a local hospital], it came back and was quite surprised when he told me that, well, there wasn’t a whole lot of doubt [that it was cancer] (white male, 50s, radical prostatectomy, <3 years post diagnosis).

Clearly, PSA screening was integral in diagnosing prostate cancer for many of the men interviewed – a number of whom had specifically sought out the test as part of their efforts to be proactive about their health. This appears to be a common phenomenon in Canada, as a recent study found that almost 50% of Canadian men over the age of 50 reported receiving PSA screening during their lifetime, despite the fact that national guidelines do not recommend it (Beaulac, Fry and Onysko 2006). While PSA screening was supplemented by other diagnostic procedures such as biopsies of the prostate, without the PSA test, the prostate cancer would likely never have come to light in a number of the study participants.<sup>5</sup> The experiences of such men demonstrate the ways in which regular PSA testing tends to produce a risk state that is strikingly disease-like, leading to increased surveillance and invasive (and often painful) intervention, and an acute experience of uncertainty about the future (Aronowitz 2009).

### **Prostate cancer and the need to ‘get it out’**

One recurring theme expressed in both support group meetings and individual interviews was that once cancer was diagnosed it was imperative to “get it out”. Importantly, men talked not only of their own desire to get “rid” of the cancer, but of the pressure they received from healthcare professionals and family members to remove it.

During the fieldwork period a radiation oncologist came to talk to the group about the PSA test and active surveillance and the following exchange was recorded in field notes:

Dr Y talks about ‘insignificant cancer’ – although he says he is uncomfortable using the term. He says that there are a proportion of men who are not diagnosed with cancer [although they technically have the disease] who will not have problems. This occurs about half the time.<sup>6</sup> He says that from the [local hospital] estimates of overtreatment they have compiled, each year a substantial number of men are overtreated. Dr Y says that with active surveillance PSA levels are checked regularly and treatment occurs if growth of the tumour and an increase in PSA levels takes place... He then talks about one study that was done where 27% of men requested

treatment – and how that a certain percentage of people with low PSA levels will opt for aggressive treatment. Someone then asks how you can convince someone who has cancer that they don't need it removed right now. Dr Y responds that the only way to deal with this is to not call it cancer.

This question evoked a lot of muttering amongst audience members of the group and it appeared to lie at the crux of the decision the majority of men in the group made to pursue aggressive treatment: 'cancer' must be removed. As a participant in Oliffe and Thorne's (2007: 153) research with prostate cancer survivors noted: "It's either there or it isn't there... You're not going to be a little bit pregnant. If it's got cancerous tissue, it's cancerous tissue, isn't it?" (Oliffe and Thorne 2007: 153). Such attitudes speak to the ongoing currency of cultural associations between cancer and death (see Sontag 1990; Balshem 1991). The diagnosis of 'cancer' therefore led men to assume that removing the cancer was their only real option – the unspoken assumption was that leaving the cancer untreated would invariably lead to an early death.

A recent literature review on patient decision-making for localised prostate cancer (Zeliadt *et al.* 2006) affirms the primacy of cancer eradication in men's treatment decisions. This desire to "get it out" was also strongly evident in individual interviews. For example, when David, a man in his 80s who had recently experienced a PSA-recurrence, reflected back on his initial diagnosis with cancer and his decision to have a radical prostatectomy he noted:

He [the doctor] said, 'You know the best way is to have it out rather than leave it in and try other alternatives' at that time. You know, it's funny when you look back and it's 15 years and a lot has changed in 15 years. I don't know if I would have the same operation again, who knows? Most probably would because if it's cancerous we might as well take it out (white male, 80s, radical prostatectomy, >10 years post diagnosis).

Evidence of the role of physicians in pushing aggressive treatment options was also evident in other interviews:

Kevin: And he [the urologist] said 'Well, how old are you now? So you have genetic life potential of probably 30-35 years.' So he said, 'You know, watchful waiting isn't a good blah, blah', and they called it watchful waiting and that kind of active surveillance, but he said, 'You know, that isn't a good option for you.' And he said, 'There are other things that aren't a good option either.' So he said, from his perspective, really there was two options, that were good options, to try and achieve as much of my genetic life potential as possible. One he said was surgery, and he said the other one was brachytherapy. And he didn't explain an awful lot more about the brachytherapy thing (white male, 50s, radical prostatectomy, <3 years post diagnosis).

John: Now I remember the first time he [the urologist] says ‘You’re not going to die from this, first of all, but I recommend having a radical prostatectomy.’ So it’s two doctors now have said [the same thing], yeah, I’ve got two opinions on that. And he said that if you have a radical prostatectomy, you’ll have a chance at the following, and he listed off a bunch of stuff... And she [his wife] says ‘You’ll have a radical prostatectomy and that’s it.’ So that was my decision making, so my decisions were all made (white male, 50s, radical prostatectomy, <6 months post diagnosis).

Given the importance of physician recommendations in determining prostate cancer patients’ treatment choices (see Zeliadt et al. 2006), it is hardly surprising that most of the men interviewed elected to have a radical prostatectomy over brachytherapy, lending weight to Fayerman’s (2009) observation that the availability of local treatment options “is more a function of ‘supplier-induced demand’ than patient choice.” However, as John’s experience shows, this pressure to ‘get it out’ was placed on men not just by healthcare professionals, but also by family members – something also highlighted in informal conversations with women in the group. For example, in describing her husband’s treatment trajectory, one woman who regularly attended group meeting noted that when her husband was initially diagnosed with prostate cancer, she just wanted him to “get it out”. She went on to discuss her unhappiness with the twelve-week delay between his decision to have a radical prostatectomy and the scheduling of the surgery. Prior research on this topic (see Zeliadt et al. 2006) has also highlighted the role that family members play in men’s decision making.

### **PSA as an index of cancer and the impossibility of cure**

PSA levels were a regular feature of conversation amongst participants in the support group in ways that made it apparent that they were seen to provide a direct and straightforward correlation to the existence of ‘cancer’. For example, during the question and answer period following a talk on erectile dysfunction, an audience member recounted his experience of prostate cancer as follows:

He says that he was diagnosed with prostate cancer 5 years ago and had a Gleason of 8. He did not have surgery but was put on hormone treatment and his PSA reduced from 5.6 to 0.4 – although he still had some of the ‘bad boy cells’. After a time it [his PSA score] started to go back up again and he went on a different hormone treatment and it [his PSA score] went down again. Now it [PSA level] is going back up again but there are no more hormone treatments.

This understanding as PSA as a direct index of cancer was also evident in the ways men discussed their PSA levels in individual interviews. For example, according to Nick:

And when you hear you’ve got cancer you think ‘I’m going to die in six months’, that’s the first thought. And when you go to the support group, talk to guys who look fine, feel fine, have no detectable PSA seven years after treatment, and I think that’s probably the most reassuring thing I got

out of that [going to the support group] (white male, 50s, radiation, <1 year post diagnosis).

This importance placed upon PSA levels as an index of cancer meant that PSA tests became critical to the lives of support group members after treatment as a way of monitoring whether the cancer had reoccurred. Thus, in his interview Kevin talked about his concerns about the possibility of recurrence, concluding that “maybe I shouldn’t be just waiting from PSA test to PSA test, worrying about whether or not this will be the time when I needed to have follow-up treatment”.

It was clear that many of the men in the support group equated a slight rise in PSA levels with cancer recurrence, experiencing considerable anxiety when levels rose above 0.5. For example, during an informal conversation following one meeting, a man noted that when he finished treatment he was told that he was “cured” but that this wasn’t the right word as his PSA levels had risen slightly. Importantly, guest speakers often reinforced this view that any increase in PSA levels post-treatment was a sign of recurrence. Thus, after a guest lecture on new developments in radiation therapy, the following exchange was recorded in field notes:

An audience member asks if there is a point in which the PSA rise becomes dangerous when it occurs after radiation therapy. The speaker indicates that a PSA rise means that the cancer is coming back. Another participant then asks what you should expect PSA readings to be after radiation. The speaker responds: ‘low – the lower the better. Ideally, 0.5 and we would like it to stay there’. Someone then asks the speaker if there is a point in time when we can assume that cancer is cured. The speaker responds: ‘there is no one absolute cut off’. He continues that if you have a lower PSA in the long term, you can be more optimistic. After 8 years of a low reading, the relapse rate is fairly low. Thus, the odds are pretty good.

Significantly, it is impossible to measure zero on the PSA test (McCleod 2005: S30) – which makes this particular form of measuring disease recurrence qualitatively different from traditional imaging technologies such as mammography, PET scans, colonoscopies and ultrasounds, with their focus on diseased organs. For prostate cancer survivors, the existence of prostate cancer as measured by their PSA levels is a matter of degree. How, then, does this impact the subjective experience of prostate cancer survivorship?

Ironically, in spite of their initial experience of cancer as something that needed to be removed, and the aggressive steps that the majority of men in the group took to get their cancer out, prostate cancer survivors often spoke of the disease as something that was largely incurable. There was a striking sense of inevitability in some men’s accounts of the possibility of recurrence and PSA levels were woven in interesting ways into these stories about the essentially incurable and chronic nature of prostate cancer. Thus, questions how interviewees defined their present status generally led to responses similar to the examples below:

Paul: Dr. X told me I was cured... but there's no such thing, of course. I know better, okay... It was only later that I learned that that is not a good word, because it's a chronic disease. And I'm finding that almost everybody in the group, after 12,13,14 years it comes back. And I'm at that point, and my PSA is still 1.3, the same it was last year. But anyway, I can look forward to the possibility of it going up. It seems to recur within 15 years.... [T]here's no such thing [as a cure]; it's a chronic disease, no such thing. The only thing that cures us is death (white male, 70s, radical prostatectomy, >10 years post diagnosis).

Kevin: ...I am cancer-free based on the current level of measurement that they can actually do. But I would also explain if someone was interested that in the long term or maybe in the short-term there is some, certainly a fairly strong, possibility of some sort of reoccurrence... But this is probably fairly slow-growing, at this point in time, and I know it can switch, but at this point in time is a relatively slow-growing cancer (white male, 50s, radical prostatectomy, <3 years post diagnosis).

We do not wish to overstate the differences between prostate and other cancer survivors here, because adults who have been 'successfully' treated for cancer are generally not seen as cured; rather, they are in remission – a state of profound ambiguity (Comaroff and Maguire 1981; see also IM/NRC 2005). This sense of ambiguity is present in the accounts of many people 'successfully' treated for cancer and poses a fundamental challenge to the modernist assumption that people are either sick or cured (Frank 1991). Thus, all cancer 'survivors' similarly experience their cancer 'survivorship' as a chronic disease dominated by reading the body for signs of future problems, negotiating different secondary prevention measures, and making decisions about the future (Aronowitz 2009).

However, we would speculate that the PSA biomarker with its attendant emphasis on *degree* of disease, rather than presence or absence of disease, might impact the experience of cancer survivorship in qualitatively different ways than for survivors of cancers where such biomarkers do not exist. As Clark *et al.* (2003) and Rose (2007) note, most people still imagine their bodies at the 'molar' level: at the scale of limbs, organs, tissues, etc; however, biomedicine increasingly visualises life at the molecular level in terms of genes, molecules and proteins. "The clinical gaze has been supplemented, if not supplanted, by this molecular gaze, which is itself enmeshed in a 'molecular' style of thought about life itself" (Rose 2007: 12). Clark *et al.* (2003) argue that the rise of the molecular gaze has therefore contributed to the emergence of new subjectivities and identities (see also Sulik 2007).

Although this phenomenon has been little studied, there is some evidence of similar experiences amongst survivors of other cancers where serum biomarkers have become common in monitoring disease status. For example, several studies of women with recurrent ovarian cancer (Howell, Fitch and Deane 2003; Hamilton 1999) have noted the prominence that the CA-125 biomarker comes to play in women's experience of living

with the disease. According to Hamilton (1999: 339):

Many women begin to identify their CA125 levels of the evidence of disease status. If it is low, they feel relieved and in control... If the level is elevated from prior levels, they know the disease is back and must plan for more treatment. *Unfortunately, even normal insignificant fluctuations in CA125 levels take on enormous meaning.* As a result, emotional well-being may come to depend on lower CA125 number, *even if numbers remain in the normal range. Patients may find themselves on an 'emotional roller coaster' with ups and downs determined by the direction of serum blood levels* (Hamilton 1999: 339; emphasis ours).

Despite similarities in the accounts of prostate and ovarian cancer survivors, it is worth noting that while perceptions of felt risk may be similar, women with ovarian cancer are far more likely to die of their disease than prostate cancer survivors. As previously noted, biochemical recurrence as measured by PSA does not necessarily correlate with clinical recurrence and a shortened lifespan.

### **Discussion**

There can be no doubt that the introduction of PSA screening has had a significant impact on the lives of men both diagnosed with and treated for cancer. Despite the ongoing controversies surrounding PSA screening for prostate cancer and its use in monitoring disease recurrence, for the majority of men in the prostate cancer support group, PSA played a critical role in their lives both pre- and post-treatment.

As McLeod (2005) notes, patients increasingly expect the PSA test to be provided to them and at times demand it. Indeed, several of the men in the present study sought out the PSA test and saw it as a way of being 'proactive' about their health despite, in some cases, being aware of its limitations. Such responses speak to the ways in which the utilisation of cancer screening technologies becomes connected with ideologies of 'responsible' citizenship.

Once adopted, PSA screening demands action if the 'risk' of cancer is realised, even if the actual risks posed by this cancer are minimal. As one of the men in the support group asked after a guest lecture on active surveillance: "how can you convince someone who has cancer that they don't need it removed right now?" The speaker's response that the only way to deal with it is "not to call it cancer", speaks to the culturally loaded nature of the diagnosis and the difficulties of offering options such as 'watchful waiting' (even if relexicalised as 'active surveillance') as an alternative to aggressive treatment. As Aronowitz (2009) notes, cancer terminologies currently evidence a semantic slippage between the ways that risk and disease are classified and named, encouraging decision-making styles typically used in symptomatic and more advanced cancer.

In light of their fears about death and debility, men are prepared to undergo possibly substantial side effects because they perceive them as the price they are prepared to pay

for escaping an early death. It is therefore unsurprising that studies (e.g. Davison, So and Goldenberg 2007) have found that few men regret having a radical prostatectomy at one year post-treatment – because they understand the treatment to have *saved their lives*. Introducing widespread PSA screening into a cultural context where cancer equals death and the earlier cancer is treated the better, it is inevitable that the majority of men will choose aggressive treatments. However, it is striking that considerations of the ethics of PSA screening (e.g., Ustun and Ceber 2004) rarely acknowledge the broader cultural meanings of cancer and the ways they impact implementation, utilisation and consequences of such technologies.<sup>7</sup>

Importantly, PSA levels continued to be a constant source of focus and discussion after the completion of treatment amongst participants in the support group. The frequency and familiarity with which prostate cancer survivors speak about PSA levels has been often noted (if little explored) in previous studies (e.g. Chapple and Ziebland 2002, Oliffe and Thorne 2007). Oliffe (2009) has suggested that PSA becomes a sort of “coded” dialogue that allows prostate cancer survivors to talk about cancer in an indirect way not understood by men without the disease; it also allows men to talk to each other about the cancer ‘matter-of-factly’, without overt reference to the emotional aspects of the disease.

Significantly, PSA levels appear to impact men’s experience of prostate cancer survivorship itself in distinctive ways. Men’s accounts suggest that they initially visualised their cancer as a discrete tumour growing within their body that could be excised, thereby leaving them cancer-free or ‘cured’. However, as prostate cancer ‘survivors’, men often talked of prostate cancer as a chronic disease, several suggesting that cancer cells remained inside of them, although presently slow growing or dormant. While this is perhaps a more biomedically accurate way of thinking about cancer (which has never fit the acute/curable disease model particularly well), the contrast it poses to their initial assumptions about cancer is striking. We therefore suggest that the use of PSA as the primary means of disease surveillance, may facilitate the perception of the ongoing ‘presentness’ of cancer. The experience of bodily instability and uncertainty that all cancer survivors experience may be substantially heightened by PSA monitoring, with its intrinsic fluctuations and the impossibility of registering a PSA score of zero.

Serum biomarkers are being used to monitor recurrence for more and more cancers, whether it be PSA for prostate cancer, CA125 for ovarian cancer or the various serum proteins now linked with breast and testicular cancer. These technologies that diagnose, assess (and produce) risk on a molecular and genetic level are increasingly supplanting older imaging technologies (Rose 2001, 2007; Robertson 2001; Clark *et al.* 2003). This shift entails a potentially radical reconfiguration of the way that the body and cancer itself are understood (Clark *et al.* 2003; Sulik 2009). We are not intending to suggest that this reconfiguration is necessarily disempowering for cancer survivors. As Clark *et al.* (2003: 185) note, “instead we see new forms of agency, empowerment, docility, subjugation, citizenship, subjectivity and morality”. However, the role of these new forms of technology on the subjective experience of cancer survivorship does require considerably more recognition and exploration.

### *Study limitations*

Clearly, this study has limitations and the findings of this research require “ethnographic testing” elsewhere (Sanjek 2000: 286). First, it is based on understandings of PSA elucidated in the context of a single support group. As only a small proportion of men with prostate cancer attend such groups (Olliffe et al. 2008), they are not necessarily representative of men with prostate cancer more broadly. Indeed, there are some indications that men who attend such groups are likely to view the PSA test positively<sup>8</sup> (Chapple *et al.* 2002a) – and the implicit support of PSA testing is evident in the names of a number of prostate cancer survivor support organisations (e.g., ‘PSA Rising’).

It is also unclear whether these perceptions of PSA reflect pre-existing understandings, or are created through the dynamics of the support group. Mathews’ (2000: 399) ethnographic research on a breast cancer support group would suggest that the support group itself “play[s] a crucial role in the development and transmission of synthetic cultural models designed to mediate conflicting beliefs and promote cohesiveness and shared identities among group members”. In a similar way, men in PCSGs may learn particular ways of ‘reading’ PSA through their group membership.

### **Conclusions**

Overall, as a result of PSA screening a significant proportion of men are diagnosed with a disease that would never have emerged clinically, treated aggressively for the malignancy, frequently requiring further treatment for the harms resulting from the intervention. They are then monitored through ongoing PSA testing and subjected to the whole process all over again in the context of PSA-recurrence. The emotional, physical and economic costs of such screening and surveillance are therefore substantial, particularly for the men diagnosed with latent cancers through this process.

There is clearly a need for further research into prostate cancer survivors’ understandings of PSA as monitoring tool and its subjective impacts of on their lives after treatment. In light of the ongoing debates about PSA screening and its merit as a tool in reducing mortality and morbidity from the disease it is crucial that the voices of prostate cancer survivors are factored into assessments of the benefits and limitations of this health technology.

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## Notes

1. Recent research (e.g., Allagiu *et al.* 2009) has also begun to explore the association of high-grade prostate cancer with mutations in the BRCA1 and BRCA2 genes, which may ultimately prove valuable in helping to evaluate appropriate therapeutic options for men diagnosed with the disease.
2. Implicit recognition of this is evident in the medical joke that PSA actually stands for “patient-scaring antigen” (see McLeod 2005: S29).
3. Although there is some evidence (Donovan *et al.* 2003) to suggest that the name used to describe this treatment impacts its acceptability to men – with ‘active surveillance’ viewed more positively than ‘watchful waiting’.
4. Historically, T1B cancer was only picked up incidentally as a result of resecting the prostate for other conditions such as benign prostate hyperplasia. However, with the advent of the PSA era, the incidence of such cancers picked up incidentally has decreased, in part because they are being detected through PSA screening (Jones, Follis and Johnson 2009). Indeed, the advent of the PSA era saw the introduction of a new category of T1 (non-palpable) cancers introduced: T1C, to deal with cancers discovered through such screening (Whittington and Vaughn 2006).
5. Because of the generally slow-growing nature of the disease, autopsy studies of men who died of causes other than prostate cancer, found prostate cancer in 30% of men in their 50s, and 80% of men in their 70s (see Breslow *et al.* 2006).
6. It is interesting that the speaker used the term ‘proportion’ to describe a statistic approaching 50%. It seems likely that he was trying to temper his representation of overtreatment in light of the fact that virtually all of the men in the audience had chosen to treat their cancer aggressively. Indeed, at the end of the talk, few men in the audience seemed to seriously engage with the concept of prostate cancer overtreatment – and the fact that a number of them were dealing with iatrogenic side effects related to treatment for a disease that may not have affected them if left alone.
7. Much of the literature on PSA screening focuses on the need for ‘informed decision making’ amongst men seeking out the test. The finding that men still view the PSA test positively once they have been ‘informed’ of its limitations (Watson *et al.* 2006) can only be explained by recognising the broader cultural meanings and context of cancer.
8. Indeed, there was one man in the support group who refused treatment and refused to monitor PSA levels after his diagnosis with prostate cancer. Other members spoke about him as an ‘enigma’. According to one man: “it’s fine to decide against treatment but you need to be able to monitor how you are doing”. For this man, and other members, PSA was a critical component of ‘responsible’ cancer survivorship.

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