Cancergazing? CA125 and post-treatment surveillance in advanced ovarian cancer


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Keywords: Australia; New South Wales; Ovarian Neoplasms; CA-125 Antigen; Anxiety; decision making, surveillance, medical gaze

Acknowledgements:
This research was funded by National Health and Medical Research Council Project Grant number 402601. The authors wish to thank the women who generously gave up their time to participate in this study at a difficult time in their lives.
Abstract

Post-treatment surveillance of advanced ovarian cancer involves regular testing of asymptomatic patients using the CA125 test. This practice is based on a rationale that is not supported by evidence from clinical trials. This paper aims to stimulate critical reflection concerning the effect of investigative tests on clinical decisions and interactions, and the experience of illness, particularly in the context of advanced malignant disease. Drawing on the idea of the “medical gaze”, and building on previous health communication research, we present an analysis of in-depth interviews and psychometric tests collected in a prospective study of 20 Australian women with advanced ovarian cancer conducted between 2006 and 2009. We describe the demands placed on patients by the use of the CA125 test, some hazards it creates for decision-making, and some of the test’s subjective benefits. It is widely believed that the CA125 test generates anxiety among patients, and the proposed solution is to educate women more about the test. We found no evidence that anxiety was a problem requiring a response over and above existing services. We conclude that the current debate is simplistic and limited. Focussing on patient anxiety does not account for other important effects of post-treatment surveillance, and educating patients about the test is unlikely to mitigate anxiety because testing is part of a wider process by which patients become aware of a disease that – once it has relapsed – will certainly kill them in the near future.

Introduction

Ovarian cancer is the sixth most common cancer in women, and 75% women who are diagnosed with it are found to have advanced disease. Initial treatment usually involves surgery followed by several cycles of chemotherapy. If initial treatment is successful, the patient will go into remission. For a minority of patients, the disease will never return. For the majority there is a high likelihood of recurrence: almost all women with advanced disease will experience recurrence at a median of 15 months after diagnosis, and once the disease recurs, it is regarded as incurable (Hennessy, Coleman & Markman, 2009). Thus the primary goal of subsequent treatments is to secure additional periods of remission and maximise quality of life. The longer the interval between treatments, the more likely the disease is to respond to re-treatment with the same drugs (Harries & Gore, 2002). The typical prognosis, however, is one of increasingly shorter remissions, followed eventually by disease that is resistant to available chemotherapeutic agents and “refractory” to treatment generally, whence the primary goal of medical care shifts again to palliating symptoms.

A longstanding and ongoing controversy in the treatment of advanced ovarian cancer concerns use of the CA125 test (Rustin, Nelstrop, Bentzen, Piccart & Bertelsen, 1999; Goonewardene, Hall & Rustin, 2007; Gadducci & Cosio, 2009). CA125 is a serum marker produced by ovarian cancers and by irritation of the body’s internal surfaces. It is used routinely in combination with other investigations to diagnose ovarian cancer, to assess response to therapy and to monitor patients for recurrent disease. The latter practice is also known as post-treatment surveillance. Like many other tests, the results may be read as a continuous quantitative measure and also as a dichotomous categorical measure that is “normal” or “abnormal” depending on whether the result is above or below the threshold of 35 mg/L.

Post-treatment surveillance is based on the assumption that patients stand to benefit if recurrent disease is treated early – that is, before patients would otherwise experience symptoms that are intrusive enough to lead them to seek treatment again. Early detection of recurrent disease makes sense if patients stand to benefit from earlier treatment of recurrent disease. This assumption is not supported by empirical evidence, however. A recent randomised trial (OV05/55955) enrolled 1,422 women with ovarian cancer who were in complete remission following first-line chemotherapy and who had normal CA125 levels. They were recruited from 59 sites in 10 countries between 1996 and 2005. Their CA125 was measured every 3 months and when it exceeded twice the upper limit of
normal, they were randomised to either immediate treatment or to continue ‘blinded’ CA125 measurements with treatment commencing when they had symptoms of recurrence. Second-line chemotherapy started a median of 5 months earlier in patients randomized to the immediate treatment arm, with a median follow-up of 49 months from randomisation. There was no evidence of a difference in overall survival between the immediate and delayed treatment arms and there was a non-significant trend towards a reduced quality of life in patients who received second-line treatment on the basis of rising CA125 levels. The authors conclude that there is “therefore no value in the routine measurement of CA125 in the follow-up of ovarian cancer patients” (Rustin & van der Burg, 2009; Chitale, 2009).

This evidence has arrived a decade late. In its absence, post-treatment surveillance has become entrenched as standard practice. Many patients thus learn from their test results that they are probably facing a recurrence, but their oncologist is likely to recommend that treatment be delayed until they experience symptoms. This “treatment interregnum” may last from months to more than a year, and it is widely acknowledged to be challenging for both patients and clinicians. A long-standing explanation for this is that clinicians and patients share a bias towards therapeutic action which makes “watchful waiting” difficult (Parsons, 1951, page 466). What is new in this clinical context is increased availability and use of investigative tests such as the CA125 assay, and the effect that these have on clinical decisions and interactions, and the experience of illness. This paper aims to stimulate critical reflection on the use of tests, particularly in the context of advanced malignant disease. This is particularly important given the prejudicial and limited way the issue has been discussed in the literature to date.

There are numerous reports of high levels of anxiety associated with CA125 testing. This phenomenon has come to be referred to in medical literature using a set of terms which more or less imply that it constitutes a specific kind of psychopathology. These terms include ‘checkup anxiety’, ‘CA125 anxiety’, ‘CA125 preoccupation’; ‘CA125 obsession’, ‘CA125 addiction’, and ‘CA125 psychosis’. The condition is usually attributed to patients, although it is sometimes seen to affect oncologists as well (e.g. Harries & Gore, 2002).

These terms clearly signal that CA125 testing creates problems, but they explain little. To date, only one study has inquired into the cause of the observed anxiety. Parker, Kudelka, Basen-Engquist, Kavanagh, de Moor & Cohen (2006) found that patient anxiety about CA125 testing is inversely related to knowledge of the test, and concluded that the anxiety might be mitigated by improving patients’ knowledge of the testing regimen. Because of its cross-sectional design, this study provides only weak evidence of the causal relationship assumed in the conclusion. It is also open to a more fundamental criticism that the underlying hypothesis about the relationship between knowledge and anxiety is simplistic.

In this paper we present an alternative explanation of the observed anxiety. It is based on two broad premises. The first is that an increasing degree of technological sophistication is being brought to bear in diagnostic testing, and as a result, medicine comes to “see” deeper and deeper into the hidden recesses of the body. The second is that patients are increasingly regarded and treated as autonomous or “self-governing” individuals, and the more this occurs, the more they are initiated into medical ways of seeing and knowing, and the more they come to interpret and understand their own bodily experience in medical terms. We aim to describe how the effects of these trends play out in the context of gynaecological oncology, drawing on theory and empirical observations. First, we review the concept of the “medical gaze”. We then review a previous qualitative study of testing in a different clinical setting. Finally, we report and discuss findings from a prospective study of 20 Australian women diagnosed with advanced ovarian cancer.
The medical gaze

In general terms, ‘the gaze’ refers to a particular way of looking at or otherwise coming to know the world. The idea of a specifically medical gaze was articulated by Foucault (1976), to account for “the way medicine has perceived things ... [and] the technique by which medicine came to have knowledge of bodies, that is came to see their interiors, organs, tissues, constancies, and variations” (Armstrong, 1987). Use of the CA125 test in gynaecological oncology is constitutive of the medical gaze in that it provides a means of detecting cancer in the hidden recesses of the body, of discerning its response to therapy, of watching for its recurrence and – as evidenced by its extensive use in clinical trials – of producing knowledge about ovarian cancer.

Foucault is best known for linking the knowledge and practices of particular disciplines with the operation of disciplinary power. This link was explored in his later work which described how individuals in modern institutions such as prisons and hospitals are subjected to techniques of monitoring and surveillance that serve to define and control them. Importantly, those who are subjected to the gaze come to internalise it themselves and “relay” it through hierarchical social networks. In this way, power and social control become less “top-down” and instead come to permeate society, with individuals monitoring and controlling each other (Heaton, 1999). The end result is that individuals are increasingly implicated in monitoring themselves. This largely obviates the need for power that is imposed from the “top down”, and accordingly, the self-governing or “autonomous” individual is seen as the end product of modern forms of social control.

This account of disciplinary power is frequently criticised for not allowing sufficient scope for the agency of those who are subjected to it: “Under the scrutiny of the gaze ... the patient becomes the passive and silent object of medical knowledge” (Rendell, 2004) – or an unwitting conduit of the medical gaze (Heaton, 1999). Interpreters of Foucault are divided on the question of how much his work evolved so as to deal with this criticism, but the issue has been taken up in subsequent literature in ways that are germane to this paper. Broadly speaking, the agency of patients has been conceptualised in two different but complementary ways, that is, in terms of resistance to the medical gaze or in terms of accommodation of it. Rendell (2004), for example, explores two different strategies of resistance in the context of AIDS treatment. One is simple refusal. In the context of the present study, an obvious example of this would be point-black refusal to undergo the CA125 test. A more intriguing proposal is that, even where patients submit to the medical gaze, resistance may arise through a “competing” gaze as the sick person comes to scrutinise his or her own body.

Rendell’s example of the latter strategy is a form of creative expression (i.e. film), but in light of findings reported here, the idea may have wider application. Armstrong and Murphy (2008) account for agency by exploring how consumers of information about cancer screening tests accommodate medical ideas and concepts by interpreting them in light of their life experience and by incorporating them into sophisticated, hybrid forms of knowledge. The authors also report frank resistance on the part of a few consumers in their study who ignored or rejected medical explanations rather than accommodating them.

In this paper we shall attempt to signal how the use of CA125 gives rise to both possibilities (i.e. resistance to and accommodation of the medical gaze), but we also stress the powerful “labelling” effects of the testing, and argue that this should be a primary consideration in any evaluation of its clinical utility.

Multiple meanings of test results

In medicine, the results of diagnostic tests are understood to have “properties” (e.g. sensitivity and specificity) that are determined empirically, and that quantify the probability that a test result accurately represents a state of affairs in the body. Medicine is thus concerned with a relationship of truth: To what extent does a symbolic reality (a test result) truly represent something in the “real” or non-symbolic world (e.g. the dissemination of metastatic disease in the body)? Researchers in health communication have recently brought a different perspective to the interpretation of test results – one oriented to meaning rather than truth. An orientation to meaning is largely concerned with
relationships that are internal to human communication (and therefore internal to symbolic reality). This entails asking questions such as: What do people mean when they refer to a test result in their talk? What meaning do people attach to test results when they hear others refer to them? Is the sender’s meaning the same as the receiver’s meaning, or are they different (in which case there is likely to be a communication problem)?

Moore, Candlin & Plum (2001) applied this perspective to diagnostic testing in the HIV treatment setting. They argued that the “availability of glosses for medical terms such as viral load does not guarantee that patients or doctors will use them with an agreed or consistent meaning”. Accordingly they investigated what doctors and patients meant when they actually referred to measures of HIV viral load in clinical consultations, and they found four different but systematically related meanings:

1. A human biological property (i.e. the amount of HIV in the bloodstream)
2. An indicator of treatment effectiveness
3. An indicator of the degree to which the patient is complying with medical treatment
4. An indicator of wellness

They also found that each of these four different meanings of HIV viral load map onto an evaluative interpretation of a given test result (i.e. a judgement of whether it is a good or bad test result) which is negotiated in clinical interactions. They argued further that the meanings are each associated with distinct “discourses of health”, namely: health as something measurable (meaning 1); health as something effected by healthcare (meanings 2 and 3), and health as something experienced (meaning 4). They illustrate the complexity generated in doctor-patient interactions as speakers shift between the different meanings of ‘HIV viral load’, and argue that in order to arrive at a shared decision about treatment, physicians and patients are faced with the difficult task of “aligning” with each other on the interpretation and evaluation of test results.

One of the aims of the analysis presented below is to determine whether the foregoing insights about multiple meanings of test results are also applicable in this treatment setting.

Methods

The analysis presented here draws on in-depth, semi-structured interviews and the results of psychometric tests collected in a prospective study of women with advanced ovarian cancer conducted in Sydney, Australia. Ethical approval for the study was granted by Sydney West Area Health Service and the University of Sydney.

Sampling and recruitment

A sequential sample of 20 women was recruited through the Gynaecologic Oncology Service of the Sydney West Cancer Network. Patients were eligible for the study if they had a confirmed diagnosis of stage III or stage IV ovarian cancer; if they were 18–79 years old and if they spoke enough English to participate in an interview. Patients were excluded from the study if they lived outside greater metropolitan Sydney, if they had significant psychiatric morbidity, or if they were unlikely to survive long enough to complete at least two interviews. Participants were recruited at diagnosis (n=11), first recurrence (n=4) and refractory disease points (n=5).

Data collection

Participants were interviewed at four month intervals over 2.5 years from 23/10/2006 to 19/06/2009 or until they were lost to follow-up. In the initial interview, they were invited to tell the story of their illness, and they were asked to update it at the beginning of each subsequent interview. The interviewer also drew on a list of pre-formulated questions (none of which initially mentioned the CA125 test), and was free to ask spontaneous questions at any point for the purpose of clarification or to garner more detail. At the end of each interview, participants completed the
Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The interviews were digitally recorded, transcribed by the interviewer, and anonymised.

Coding and analysis
For the purposes of this analysis, all talk relating to the CA125 test was extracted and systematically coded, initially using the categories proposed by Moore, Candlin & Plum (2001). Additional coding categories were created as necessary. Average anxiety and depression scores were calculated for each participant and across participants for each interview. The data were considered in relation to the literature referenced above and throughout the remainder of this paper. The team worked towards interpretive consensus through discussion of results in team meetings, and in the process of drafting this paper.

Results
Participant characteristics are summarised in Table 1. A median of 3 interviews was conducted with each participant (range 1 to 5). Table 2 shows the distribution of interviews by disease point. At the end of the study period, 11 participants were known to have died and two had withdrawn from the study for other reasons.

Table 1. Participants

<table>
<thead>
<tr>
<th>Ethnic background</th>
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<tbody>
<tr>
<td>Anglo Australian</td>
<td>10</td>
</tr>
<tr>
<td>Immigrant</td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>3</td>
</tr>
<tr>
<td>Europe</td>
<td>1</td>
</tr>
<tr>
<td>India</td>
<td>1</td>
</tr>
<tr>
<td>Asia</td>
<td>1</td>
</tr>
<tr>
<td>South America</td>
<td>1</td>
</tr>
<tr>
<td>Pacific</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>20</td>
</tr>
<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Children</td>
<td></td>
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<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
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<tr>
<td>Median age at diagnosis</td>
<td>51.5 yrs (range 25–68)</td>
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</table>
Table 2. Interviews

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<table>
<thead>
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<th></th>
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<tbody>
<tr>
<td>Initial diagnosis</td>
<td>6</td>
</tr>
<tr>
<td>1st remission</td>
<td>17</td>
</tr>
<tr>
<td>1st recurrence</td>
<td>10</td>
</tr>
<tr>
<td>Subsequent remission</td>
<td>6</td>
</tr>
<tr>
<td>Subsequent recurrence</td>
<td>4</td>
</tr>
<tr>
<td>Refractory disease</td>
<td>11</td>
</tr>
<tr>
<td>TOTAL</td>
<td>54</td>
</tr>
</tbody>
</table>

Average depression scores for all participants were all less than 6, which is within the healthy range. The majority of participants (n=13, 65%) had average anxiety scores within the normal range. Of the remainder, two had average scores consistent with mild anxiety (8-10), and two had average scores consistent with being “a clinical case” (HADS score >11), although neither suffered from severe anxiety (HADS score >16). When averaged across interviews, anxiety and depression scores were all within the normal range and tended to fall slightly at each subsequent interview. During the study, six of the 20 participants were being treated with counselling and/or medication for anxiety and/or depression.

The illness narratives all began with an account of the onset of symptoms, followed by presentation at a clinic, then diagnosis. Delays between each of these events were common. When the correct diagnosis was finally revealed, it was received with a mixture of shock and relief that the problem was finally unmasked. This in turn triggered a series of major clinical decisions, followed by therapeutic action in the form of surgery and chemotherapy.

A diagnosis of cancer tends to undermine a patient’s trust in her own body (Little, Jordens, Paul, Montgomery & Philipson, 1998). Thus the body is commonly experienced as “a house of suspicion” (Breaden, 1997), and this trope was clearly evident in the illness narratives collected in this study:

Well it’s the fear of the unknown … and that is a horrible fear, because until you’re told “No it’s not there”, or “It’s not in your kidney”, you’re imagining that it’s probably there. And I am getting a pain just sort of around here. Nothing showed up on the scan so I thought, ‘Oh it’s my liver, it’s got to be my liver or my kidneys or something’. So I don’t know why I’m getting that pain, but at least at this stage it doesn’t appear to be anything sinister. (Felicity)

As the preceding quote suggests, during diagnosis, a relationship of epistemic superiority is set up between the patient’s subjective experience and the medical gaze. The former has proven untrustworthy: it has concealed a sinister intruder that has over time thereby gained a lethal advantage. Even if the intruder managed to elude the medical gaze for a time, the latter — by virtue of its biotechnological enhancements — can see inside the body and tell the truth about what is or what is not there. Accordingly, participants construed decisions and actions as being governed by the rational use of technologies (such as “the scan” in the quote above) that extend the medical gaze, and they re-invested their trust in them.
The dynamics set up at the beginning of treatment shifted markedly during the course of treatment. Over time, participants acquired a degree of technical knowledge about their disease and its treatment, including knowledge about the CA125 test. They also learned to inhabit a body radically altered by disease. We shall describe each of these processes in turn.

Initiation into the medical gaze

The participants each acquired over the course of their treatment a degree of technical knowledge. This was evidenced in their talk by the use of technical terms, explanations of medical technicality, and accurate recontextualisation of expert views. Use of the CA125 test imposed specific demands. Participants had to adjust to the fact that there are several ways to truthfully read the one sign (i.e. as a continuous or as a dichotomous measure). They also had to adjust to the vicissitudes of the absolute value of the test results, which can vary markedly from one patient to the next. At its most elevated level, the CA125 “count” may climb into the tens of thousands or it may remain below one hundred and, counter-intuitively, its magnitude does not necessarily correlate with the volume of disease (Parker, Kudelka & Basen-Engquist et al., 2006).

As a result of ongoing disagreement about the value of the CA125 test after treatment, it is used by some clinicians and not others. Participants in this study were drawn from a cancer service where CA125 levels were tested every three months. As some clinicians involved in their care tested less frequently or eschewed post-treatment testing with CA125 altogether, many participants had to accommodate this practice variation. Some did so by accessing additional test results through their general practitioner.

The problem of inaccuracy of test results featured in this study in predictable ways as patients struggled to deal with test results that were actually or possibly false:

Penny: My CA125 didn’t go up when I was diagnosed the second time.
Interviewer: So they’re not using it now?
Penny: No they are using it but it doesn’t make much sense to me now.

Giselle: He [the oncologist] said that the CA125 was 178.... When he told me that, he said “Oh, but look, you know, sometimes if you’ve had an infection or anything like that ...”
Interviewer: Yeah, there’s other things that can throw it.
Giselle: That’s right...

Previous studies have shown that lay people have difficulty understanding the probabilistic nature of diagnostic and screening tests (e.g. Hamm & Smith, 1998), so we shall not pursue the point here. We will focus instead on the problem of multiple meanings, as this has received much less attention.

When we applied the coding categories proposed in the study of HIV testing (Moore, Candlin & Plum, 2001) to the participants’ talk about CA125 results, three of the four proposed meanings fitted the data well.

Meaning 1: CA125 as a human biological property. This meaning figured prominently in the talk about test results, and was glossed well by Irene when she said of the test that “It gives you your level of cancer in your body”. In accordance with the HIV study, when used in this sense the CA125 tended to be construed (in discourse analytic terms) as a participant rather than a process, and as the subject rather than the bearer of information:
The cancer is – CA125 as you know is high. The last time I saw Dr. Jones it was 450. The count, that is too high. (Astrid)

**Meaning 2: CA125 as an indicator of treatment effectiveness.** This meaning also featured frequently in the interviews and its use was analogous to that of HIV viral load as the bearer of information about treatment:

Treatment had worked and everything was doing okay. We knew it had been working because the CA125 had been dropping significantly so that was a good telltale sign. (Debbie)

**Meaning 4: CA125 as an indicator of wellness.** This meaning figured frequently in the interviews in different ways depending on whether test results were concordant or non-concordant with the patient’s subjective experience (Table 3).

**Table 3.** Concordance and non-concordance between CA125 and patient experience

<table>
<thead>
<tr>
<th>Subjective experience</th>
<th>CA125 test result</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Normal</td>
</tr>
<tr>
<td>Well</td>
<td>Concordance (Reassurance)</td>
</tr>
<tr>
<td>Ill</td>
<td>Non-concordance (Discounting)</td>
</tr>
</tbody>
</table>

Test results concorded with patient experience in two different ways. If a patient felt well and returned a normal test result, the test results were reassuring. If the patient felt ill and returned an abnormal result, then the test result tended to legitimate their experience:

It seems sometimes quite difficult to get the medical professional people to believe that there’s something not right .... I can remember when I wasn’t really feeling very well before, like before I was actually diagnosed, I was just sort of popped out of the room within a few minutes and it was so frustrating because I knew I wasn’t feeling very well and I don’t know how bad you have to look before people really believe that you are ill and I think, in that respect I think I’ve been pleased to have the CA125 because it seems to confirm what I feel physically. (Felicity)

As predicted in the HIV study, the discourse of health experience was more likely to feature in the talk about CA125 results where the two did not concord. Non-concordance also occurred in two different ways, that is, where patients felt well but returned an abnormal test result, and where patients felt ill and returned a normal test result. Some participants tolerated non-concordance better than others, and as reported elsewhere (Parker, Kudelka & Basen-Engquist et al., 2006), this tended to correlate with an understanding of the vicissitudes of the test:
Bella: I’m just waiting to see what this first result says to see if it’s coming down, but importantly that the symptoms go away, because now that I know how the CA125 works a little bit better I do understand it can come right down and you can still be symptomatic, and I didn’t know that. So I’m hoping for the symptoms to go.

Interviewer: So that’s more important, how you feel rather than what that number says?
Bella: What the test says, yeah, it is now.

Non-concordance was most likely to provoke anxiety where a rising CA125 indicated the likelihood of recurrent disease, but the recommendation was to defer treatment if the patient was asymptomatic. This is what we have referred to elsewhere as the treatment interregnum:

Bella: We had a follow up blood test and it was rising still so that’s pretty much telling us it’s back.
Interviewer: So at this stage are you waiting for a further check up or further tests?
Bella: Well I went to see Dr. Jones and he suggested that it might be better if we wait till February and see how the CA125 is going then. If it hasn’t gone up dramatically and I’m feeling okay, he wants to wait as long as he can before we do the chemo again to give it a chance. Because if we were to do it straight away it wouldn’t give it a good chance because it’s too soon after the last one.
Interviewer: So it might become resistant to the chemo.
Bella: I think that’s what he’s worried about. And then if I’m doing alright he’ll want to wait until May, but I have a feeling it’ll be done in February because I haven’t been feeling real well and I don’t think it’s just stress, I think it is the cancer ...

When there was non-concordance between subjective experience and test results, the test results influenced how patients reinterpreted their experience. A patient who felt well but returned an unexpected abnormal result might attach an ominous meaning to symptoms that were previously thought to be insignificant. Conversely, a patient who felt ill but returned a normal test result might discount their symptom experience:

Astrid: ... And now I’ve got pain on my back on my right side but it comes and goes, and it’s not the same pain as I had the last time, but then again that was resolved after I’ve spoken with the registrar.
Interviewer: So you still sometimes get aches and pains and worry what they might be?
Astrid: I’ve always relied on the marker, if I had a blood test and that tells me my count is normal I will [dismiss] it as muscular pain, and don’t even think about it anymore.

It is important to note that the preceding observations about (non-)concordance hold where the results of CA125 tests are accorded epistemic superiority over subjective experience, and this is contingent on the second process we discuss under the next major heading below.

Additional meanings. CA125 was never referred to as an indicator of treatment compliance (meaning 3 in the HIV study) in the interviews conducted for this study. In place of this we observed a related but distinct meaning of CA125 which was infrequent compared to the three meanings described above. This was CA125 as an indicator of self-care. (We shall refer to this as meaning 3*.) A normal CA125 reading might suggest to the patient that she is looking after herself whereas an abnormal reading might indicate the contrary. This meaning was usually invoked in the latter
circumstances, when the patient had been practising self-care but her CA125 readings were rising nonetheless:

Interviewer: So what did you think when you got that test back?
Astrid: I got a bit emotional, I must admit, the reason being, I was getting frustrated because I knew I was doing the right thing by me and my family and why did it come back? I haven’t abused myself, I haven’t, you know, my health, I haven’t abused anything ...

Learning how to inhabit an altered body

As well as being initiated into medical technicality, the participants also learned over time to “read” their altered bodies. This process involved, for example, learning how to differentiate the symptoms of cancer from the side-effects of chemotherapy or from causes unrelated to cancer. A good example of this was provided by Astrid in her fourth interview, by which time she was enduring her second recurrence. According to her own jest, she had “graduated” from the school of cancer pain, and she evidently took pride in the way this enabled her to speak from a position of knowledge, and initiate treatment in accordance with the authority bestowed by this qualification:

I can tell the difference ... you know, like, I’ve already graduated. [Laughter] Summa cum laude! [Laughter] Valedictorian! [Laughter]. I can already tell which one is which – you know, the difference between just normal muscular pain and when the cancer is back. I can now tell exactly, spot on, because I did that last [in] 2006. I was the one who knew it was back.... I went to my GP and I go, “Give me this, this, this because I need it. I think the cancer is back.” (Astrid)

The five interviews with Bella presented a similar story, but her account also reveals how the process of learning how to inhabit an altered body interacts with the process of being initiated into medical technicality. Bella’s account was initially similar to others in the study in that she construed the first recurrence as being “heralded” by symptoms and then “confirmed” by a rising CA125 count. In other words, the biomedical gaze was able to verify what experience could only intimate. By the third interview, Bella showed little interest in the test results, and signalled the waning superiority of the medical gaze in relation to her own experience:

They can’t see everything now ... Some parts they just can’t see into ... [But] I know where it is”.

In her fifth and final interview, when Bella’s disease was classified as incurable, progressive and drug-resistant and she was having palliative treatment only, Bella dismissed CA125 test results with the comment “I can feel it growing so I know how bad it is.”

Felicity never went into remission, and so (to borrow Astrid’s metaphor) she was forced to undertake a “crash course” in reading a body that was irrevocably altered. Her own success in this endeavour saw her correctly anticipating the test results, which again signals the epistemic ascendance of subjective experience over objective surveillance technology in the later phases of the illness trajectory:

“I had a sneaking suspicion that it [CA125] was elevating again and I was right. I’m amazed at how well I can read my own body. I was starting to sweat a bit more again and I was feeling very uncomfortable in my rear end and I thought, ‘Okay, this is it again’”. 
Karoline did not say she learnt to “read” her body but rather that her body “tells” her what is going on, and over time she has learned to listen:

My body tells me when things aren’t right. ...The body lets me know ... I’m more aware I suppose of what my body’s trying to tell me. There’s something wrong now.

Irene’s interview reveals something of the process by which participants come to be able to “read” their altered bodies:

“I’m very mindful of anything that’s in around my abdominal area ... and then I’ll tend to be a bit worried also about all the lumps and so on around there [indicating neck] ...”

The process is clearly one of surveillance – albeit a mode of surveillance unmediated by medical technology.

DISCUSSION

Our quantitative findings gauge the degree to which anxiety was a problem in this cohort of patients. Our qualitative findings reveal the nature and extent of the demands placed on patients by use of the CA125 test, as well as some hazards it creates for decision-making. They also reveal some of the test’s benefits and help explain why it gives rise to anxiety. All of these factors should be considered in a reckoning of the value of post-treatment surveillance. We discuss each set of findings in turn.

According to the HADS scores, only two of the 20 participants had anxiety levels that would warrant clinical attention. Neither suffered from severe anxiety and these higher scores were not sustained, so if there was a problem it was addressed. This does not suggest that most of the participants were “fine”. On the contrary, all faced a threat that could hardly have been more serious. It suggests, rather, that depression and anxiety were contained within normal levels by the women’s own resilience combined with the professional care they received. Thus we found no evidence that patient anxiety was a problem demanding a response above and beyond existing care.

Use of the CA125 test clearly places demands on the patient’s understanding. To gain a firm understanding of the results, patients must be able to interpret them as both a continuous and a categorical measure. They must also appreciate that the test is not always accurate, that the quantity of the “count” bears no relation to the volume of disease, and that the results are probabilistic in nature (i.e. they indicate only the likelihood of disease or its absence). An additional demand arises from the fact that experts disagree about the value of the test following the completion of therapy. Even if patients do not understand why experts disagree, they have to accommodate the practice variation that follows from this.

Use of the CA125 test is likely to place additional demands on both patients and clinicians by complicating communication between them. This follows from our observation that the term ‘CA125’ has a range of different meanings that can be discerned in the interviews. If we model these meanings along the lines that Moore, Candlin & Plum (2001) modelled the meaning of ‘HIV viral load’, the result is a complex local system which is represented in Figure 1 below, and which can be summarised as follows.

1. Any individual CA125 test yields a numerical quantity that simultaneously has implications in terms of each of four possible substantive meanings.
2. The diagnosed irritation may be due to cancer or to something else. This option yields meaning 1: CA125 as an indicator of cancer. Where a series of test results are available, the result will also indicate whether the cancer is growing, diminishing or stable.

3. If the CA125 is interpreted as the effect of therapeutic action, it indicates the efficacy of the action. This yields meaning 2, CA125 as an indicator of treatment effectiveness, or meaning 3*, CA125 as an indicator of self-care, depending on who is the agent of the therapeutic action (the physician or the patient, respectively).

4. If the CA125 is interpreted in relation to subjective experience (i.e. how well or ill the patient feels), it yields meaning 4: CA125 as an indicator of wellbeing. If a test result is concordant with the patient’s experience, it will either reassure her she is well or legitimate her illness. If the result is not concordant with her experience, she may either discount her symptoms or interpret them as ominous. Importantly, the possibility of the fourth meaning is conditional on the epistemic superiority of the CA125 over symptoms.

Decisions about when to resume treatment are usually the outcome of a negotiated process between patients and clinicians and they often involve other parties as well, such as the patient’s spouse or children. Investigative technologies may constitute a hazard for shared decision-making by making it extremely complex, as the various parties must reach agreement about the meaning and value of test results, and as we have shown, multiple meanings are possible. Thus the conclusions of Moore, Candlin & Plum (2001) about HIV viral load are also likely to apply in this clinical context: various meanings of ‘CA125’ may come into play in clinical consultations, each referencing different discourses of health, and mismatches between intended meanings and those that are received may undermine the alignment on which shared decision-making depends.
Figure 1:

QUANTITY

SUBSTANTIVE MEANINGS

NEGOTIATED VALUE

CA125 test

As the effect of a cause

Normal
Abnormal
Increasing
Stable
Decreasing

Irritation
Therapeutic action

Cancer
Other cause
Medical treatment
Self-care

Reassurance
Legitimation
Discounting
Ominous interpretation

Concordant
Non-concordant
Superior
Equal
Inferior

Meaning 1
Meaning 2
Meaning 3
Meaning 4

GOOD

BAD

Atkinson test

Negotiated value

Quantiative

Substantive meanings

Negotiation
Use of the CA125 test also places psychological demands on patients. In the diagnostic phase, “bad” results spark a series of decisions that lead rapidly to therapeutic action. Where testing continues beyond the completion of treatment, “bad” results are typically followed by a period of “watchful waiting”. Post-treatment surveillance thus requires patients to adjust to a different “game-plan”.

Furthermore, because this practice also makes patients aware of recurrent disease at subclinical levels (i.e. before they would normally become aware of it through symptoms), it can be seen to “contaminate” periods between treatments with the knowledge that the disease is probably recurring. This may be experienced as a psychological burden, and this consideration should not be overlooked just because the burden is not physical. If there is no benefit gained by knowing earlier that a recurrence is probably occurring (and we know from recent trials that there is no survival advantage from earlier treatment of recurrence), post-treatment surveillance extends the experience of recurrence and foreshortens the experience of remission.

The latter point can be illustrated by considering two hypothetical patients who both survive 2 years after commencing initial treatment (Figure 2). Patient A undergoes post-treatment surveillance and learns she is probably experiencing a recurrence 4 months earlier than Patient B, whose recurrence is diagnosed on the basis of symptoms. Patient B experiences a third of her survival time as remission, whereas Patient A experiences only a sixth of her survival time in remission. The effect is analogous to that of “lead-time” in mass screening programs (Hennekens, 1987, pages 341-42), where early detection of disease may simply give people more time with their diagnosis without extending their lives.

**Figure 2.**

On this note, it is important to consider how test results “mediate” the experience of symptoms. If a patient experiences symptoms during remission, and her experience is coloured by the knowledge that she is probably experiencing a relapse, the symptoms may be more unbearable.
than they otherwise would be, and she may consequently seek treatment for them earlier. This is what we have described above as ominous interpretation, and through this mechanism, post-treatment surveillance may undermine the goals of maximising the duration and quality of remission by influencing the patient so as to bring treatment forward. Effectively, it presents another hazard for decision making. Discounting is another effect of the same mediation process, but it is likely to make symptoms more bearable, and so work in favour of the same therapeutic goals. Reassurance and legitimation are both subjective benefits of testing, and may partially explain why patients say they want the tests (Palmer, Pratt, Basu & Earl, 2006).

It is also important to note that the demands, hazards and benefits of testing diminish as the truth value of the patient’s symptoms increases. It is difficult for patients to learn to “read” their bodies because a cancer diagnosis tends to undermine trust in it. If they manage to do so, however, the test becomes largely irrelevant. It is reasonable to infer, therefore, that the more clinicians assist this learning process, the earlier in each case the CA125 test will become perceived as redundant. There is no good reason to suppose that the end of testing will herald the end of anxiety, however. To make this point clearly, we offer an alternative explanation of why testing provokes anxiety.

“Cancergazing?”

Our qualitative findings suggest that patients come to make sense of their experience simultaneously by means of two radically different ways of seeing and knowing. One is the objective medical gaze, and in this treatment setting, the CA125 test plays a central role among the technologies that tell the truth about what is going on in the hidden recesses of the body. The other is subjective bodily experience, and in particular the sensations associated with progression of malignant disease, and the treatments that are used to eradicate or control it, or palliate its symptoms. Both ways of seeing and knowing the disease are accomplishments. The first is obviously an accomplishment because as a non-expert, the patient must be initiated into a degree of medical technicality. The second is also an accomplishment because the patient comes to inhabit a body that is radically altered and she must learn its ways through a process of self-surveillance. Clinicians participate in this process by providing informal instruction: the patient learns where to look, what to watch out for, and what the clinical signs portend. The more accomplished the patient becomes in this discipline, the greater the truth-value of her symptoms relative to the CA125.

We contend that whether the patient watches her cancer grow through the symbolic medium of test results or through the somatic medium of her bodily experience, she is effectively watching the progression of the disease that will soon kill her. She is cancergazing. We have deliberately chosen a provocative term to provoke critical reflection on an activity that may preoccupy patients, clinicians and lay carers in the last months of a patient’s life. In order to provoke further discussion, we will raise a final question and make a final point.

Is there one gaze or two? Is the patient simply acting as a relay of the medical gaze in relation to her own body? This interpretation makes her its unwitting conduit and a “passive and silent object of medical knowledge” (Rendell 2004). If we suppose there are two different gazes, this allows for the possibility that patients may actively accommodate the medical gaze and even resist it. On this account, she may cultivate a hybrid or “bifocal” gaze that combines radically different perspectives but is reducible to neither. (A similar idea is proposed by Prasad (2005) in the field of radiology). This emergent gaze may further be understood as an aspect of the phenomenology of advanced malignant disease [1]. The latter interpretation fits better with some of the quotes from the participants in this study who survived longest (e.g. Astrid and Bella). The emergent gaze may be generated by a process of accommodation analogous to that
described by Armstrong and Murphy (2008). In Bella’s case, the emergent gaze arguably constituted a “competing gaze” (Rendell 2004) which ultimately served as a point of resistance to the medical gaze: in the end stage of disease, she dismissed her test results event though she submitted to the test.

Our final point re-iterates an observation by Rendell (2004): “The medical gaze does not simply ‘look’, it also names.” This point was clearly illustrated above (Figure 2). Early detection of recurrent disease redeﬁnes the patient’s experience. Use of the CA125 test in post-treatment surveillance determines when and for how long the patient’s situation is labelled ‘remission’ or ‘recurrence’. Given that remission is the best a patient can hope for, it would be an oversight not to acknowledge the potential impact that this may have on the quality of the limited time remaining.

Conclusions
The current focus on patient anxiety and the proposed response to it (i.e. more education) are simplistic and limited. Focussing on patient anxiety associated with the CA125 test does not account for other important effects of post-treatment surveillance, such as increased demands on patients’ understanding and adjustment, increased complexity in communication and shared decision-making, and another hazard for decision-making that arises through “ominous re-interpretation”.

We have identiﬁed several subjective beneﬁts that patients enjoy in return for the problems created by this practice. Testing can reassure patients and legitimate their illness experience. Furthermore, the phenomenon of discounting serves one of the treatment goals in this setting. There may be other subjective beneﬁts to CA125 testing that were not detected in this study but further evidence of this is warranted to outweigh the very real demands and hazards that the testing creates.

Finally, we have argued that post-treatment surveillance is part of a wider process by which the patient becomes aware of a disease that – once it has relapsed – will certainly kill her in the near future. If we are correct, educating patients about the test is unlikely to mitigate anxiety. “Cancergazing” may well be inevitable in a social context where clinicians have a duty to inform patients out of respect for their autonomy, and it is unsurprising that the process is attended by a degree of anxiety. What is surprising is the notion that educating patients about the test might alleviate that anxiety. The current tendency to label anxious patients serves to deflect attention from the real issue: lay people and experts are both susceptible to being captivated by investigative technologies, and it is important to question their utility, especially as the end of life approaches.

Footnotes
1. We thank an anonymous reviewer for this insight.
References


