

Great PSA Debate, Prostate Cancer Support Federation, Leamington Spa, England, November 10, 2009

A Scottish (Contrarian) View

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SETTING THE SCOTTISH SCENE

In Scotland, each year 2,500 new cases of PCa are diagnosed and roughly 1,000 men die. Moreover, diagnosed cases are projected to rise by 25% by 2016.

In the Lothians, on the other hand, an average GP encounters PCa as a rare event, seeing one PCa case out of every 3,062 appointments or roughly one a year. One GP said “a low PSA result is fine but an elevated one is a headache.”

Our views are based on individual and support group experience and limited general research in Edinburgh. We patients are all experts by experience, personal and shared. We truly are a Band of Brothers thrown together and bonded by a common disease.

Edinburgh’s Western General Hospital (WGH) is one of five UK centres of urological excellence in UK and only place in Scotland to pioneer keyhole surgery. Yet Zometa is not made available but provided in Glasgow, regional SCANS (urological and related medical staff) do not communicate with each other and no national treatment standards exist in our devolved health system.

So, your experience and views well may be different from ours.

THE PSA TEST

The Scottish Government stated policy is that any man 50 years of age or older has the right to a PSA test, confirmed by the deputy CMO at our first national conference on March 12th. But, 26% of GPs surveyed in Edinburgh refused to give one when asked.

Dr. Carroll at the University of San Francisco justified testing by stating:

“The bottom line about prostate cancer testing is that we cannot counsel patients about next steps for cancer that we do not know exists.”

Right, but are men informed and counselled about what happens if they are tested positive and the significance of the result at their age? More importantly, are they informed and counselled enough at each stage in the process to realise the NHS mantra of an “informed choice?”

PSA levels are raised in two thirds of men who do not have PCa. One half would never have been diagnosed if they hadn't asked to be tested. Studies have shown that 33 to 50% of diagnosed cancers have no clinical significance. If it takes 48 men to be treated to save one life, the other 47 have been treated without changing their odds of survival, not counting the emotional trauma involved or side effects that too often occur.

Breast cancer (BCa) sufferers are facing a similar dilemma. A recent Danish study showed that if 2,000 women are screened over ten years, only one will be saved and 10 healthy women will be treated unnecessarily with part or all breast removed, radiotherapy or chemotherapy. NHS has universal screening for women over 50 and spends £100m a year on it.

Let's look at indicative testing levels: under 4, 15% will have PCa; between 4 to 10, 25% ; over 10, 50% will have PCa. But are all these cancers life-threatening tigers?

A respected oncologist at WGH said over 20 indicates cancer and 100 or over indicates it has metastasised. At lower cut-off levels, a great number of men are drawn into more over diagnosis.

Lothian data indicted that a PSA between 3 and 10 carried a 25% risk with 90% localised cancer; between 10 and 20 carried a 50 to 60% risk with 60% localised; and over 20 had a 90% risk of locally advanced or metastatic.

From 20,000 PSA tests conducted between 2001 and 2008, among men under 70 years of age with a reading of less than 3, 25.6% had cancer; and those over 70 with a reading of 5 or under, 30.1% had cancer

But, 25% of men between 40 and 60 had BPH symptoms, over 70% over 70 years and over 80% in the over 80s.

An epidemiologist of 27 years experience claims the PSA test is a bad test, because it has too many false negatives that directly leads to over diagnosis and over treatment.

However, the PSA test is all we have at the moment. So, we have tentatively concluded the following:

1. Men should have the right to be tested if they have symptoms or are worried, but results ought to be carefully explained by their GP within a context that PCa is a slow growing disease.
2. GPs should insist on at least two PSA tests over separate quarters and be sure there is an upward trend established before further tests are initiated and a diagnosis is made, demanding that the far superior free to total measure be used instead of the usual headline level.
3. We should look at higher cut-off levels and a positive DRE performed in the GP's office indicates a problem before further tests and a diagnosis are made.

4. Testing is critical to pick up T3 and T4 cancers where radical interventions can save lives especially with poor Gleason scores and a relatively young age, but the rest of men with T1 and T2 and marginal Gleason scores need to be fully informed and counselled **before any treatment is allowed**.

5. We should look at introducing screening now for **high-risk groups** that fit a clear definition. It would be a positive gesture if the NHS said they would introduce national screening for these men at risk.

To paraphrase the Bard, “to test or not to test is NOT the question.” **We believe the elephant in the room is not testing, but the informed choice process after a man has a positive PSA test.**

INFORMED CHOICE

What does “informed” really mean? And where does “choice” enter? Communication is truly an art form made better with practice to be clear. There are numerous opportunities for misunderstandings, ambiguities and overreactions.

Two thirds of the 230 men surveyed in the PASCO study reported so well in your Federation’ summer newsletter said they did **not** have a real choice.

Nobody knows what is the preferred treatment, rather urologists can’t agree and surgeons fight with oncologists for “business.” There is no standard approach, which is why the ProtecT study was initiated with 100,000 men. Unfortunately, results will not be known for at least another 5 years.

The first encouraging study on testing, the recent European study, showed a 20 to 30% improvement in mortality if a PSA test was implemented and was considered by our epidemiologist to be a good trial with proper. If you recall, 7 men would have been saved per 10,000 screened but 216 would have been over diagnosed and over treated, not much of a cost benefit.

Once a man is diagnosed with PCa, there seems to be inevitability, a sequential cascade that too often leads to radical intervention by surgery or radiotherapy. There are clear reasons why this occurs:

1. Specialists advocate their own speciality.
2. Men are mostly ill equipped to understand the significance of each treatment offered and risks of side effects that often seem to be poorly explained or understated. For example, even recent advances in keyhole surgery carry a 5 to 20% chance of incontinence and 30 to 70% chance of impotence. Moreover, the much-heralded robotic treatment, the De Vinci system, in a study of 9,000 patients since 2003 produced even higher risk of incontinence or impotence compared to open surgery. There are 19 such robotic systems operational in the UK.

3. Only educated or resourceful men are able to use the Internet for a crash course in this strange and complex disease and try to navigate their way to a decision.
4. Men have a natural tendency when hearing the Big “C” word to panic and want immediate action taken before things get worse.
5. There does not seem to be a specialist for active surveillance in most hospitals, as this option is treated more as a deferment with very little encouragement and formal support provided. Alternative substances and therapies are usually rubbished by specialists as having no clinical evidence to take seriously, leaving men with little to do themselves to manage their disease.

So, where does this post PSA confusion lead us? **We have come to the following tentative conclusions:**

1. If a man has a Gleason 7 or even a 5 or 6 and is close relatively young (early 50s), radical treatment ought to be seriously considered as a preventive step against a potentially lethal cancer.
2. Specialists need much clearer benchmarks, such as the free to total assay, for diagnosis than prevailing low hurdle levels based only on headline readings.
3. Some interim steps are needed **NOW** to prevent over diagnosis and over treatment.
4. Men will have to be educated that they might will be better off waiting than risk side effects, not to mention all the emotional trauma for them and their partners from general anxiety or, worse, depression which strikes one in four men with PCa.
5. There are some good reasons to wait:
 1. Better diagnostic tests are being developed to detect aggressive tigers from slow growing pussycats.
 2. Existing treatments are achieving more consistent outcomes with improved procedures and maybe even lower side effects.
 3. The ProtecT study will finally compare the effectiveness of one treatment against another.
 4. New treatments are coming on stream. For example, high-intensity focused ultrasound (HIFU) or photo dynamic therapy (PDT) is showing that focal therapy in a small trial achieves consistent 5 percent side effects of impotence and incontinence within one month after the operation, takes just over an hour under a GA and usually the patient is

in and out in the same day. This approach hits the 5% of prostate containing cancer, leaving the other 95% of the gland in place and functioning.

5. Importantly, there is time for men to do something themselves through alternatives to manage their own disease while waiting. At this point I would like to introduce my colleague, **Chris Garner**, who has actively managed his PCa over the last 30 quarters and has written a book on his experience with many non-invasive treatments. **Chris ...**

First a Yankee, now a Sassenach - what would Robert the Bruce say?

I've been given one minute, so hold on to your toupees.

When I was diagnosed, I had two questions -

1. What caused my cancer?
2. Are there any natural remedies?

On causes, here's the NHS view - I quote from their Risk Management Programme 2.3 "The causes of prostate cancer are not known." Full stop. Well I've been investigating this for the past 7 years and I now have an understanding of what caused my cancer.

On remedies, the good news is that they abound. The not so good news is that the NHS offers none of them. I only have time to mention a few -

1. Eat food that is truly nourishing - not easy these days.
2. Take exercise that suits and benefits your body.
3. Find a way of dealing with stress e.g. deep breathing or Tai Chi or joining a choir.
4. Live from an open and fearless heart.
5. Sleep soundly.

If any of you have poor sleep patterns - and who does not wake up in the night with the eternal question "To pee or not to pee"? - Here's a tip. Two tablespoons of honey last thing at night. We tried it in our Group. 7 men took the honey; 6 benefited.

So these remedies - and many more, as well as the causes - are written up in a book I have just finished and which the Edinburgh & Lothian Group will publish in the New Year. Although we are a Scottish organisation, the book is free and our aim is to send a copy to every Support Group in the UK.

Tapadh leibh agus slainte mhath

(Thanks and good health)

SUMMARY

Prostate cancer is a complicated and confusing disease. If you have a PSA, hope for a low score. Elevated PSA leads a man into a labyrinth of confusion and risk, not to mention emotional upset for partner and family.

It appears to be the only cancer where an ill-equipped, traumatised patient is supposed to choose his treatment. Within the context of making this “informed choice,” the PSA is almost a red herring. It behoves the NHS to become much more sensitive, honest and fully consultative at each stage in the decision making process.

Until a much better detection test is offered, as much as we are disappointed to say, national screening will have to wait to avoid herding more men into uncertain outcomes unless such screening is targeted to high risk groups.

Urologists seriously ought to consider presenting active surveillance as **the** preferred option **NOW** to men indolent PCa. After all, it is one of the top priorities recommended by N.I.C.E!

Sadly, men without symptoms will be missed unless accidentally discovered or a new test identifies them.

Time should be on the side of men facing PCa today like it never has before. Don't we owe it to our brothers to have the best chance for survival and a quality of life in their advancing years?

Thank you for allowing us to share our experience with you.