Dealing with Prostate Cancer

A cautionary tale in two Parts

by

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Notes:

In both Parts I use *italics* to draw attention to something that is *important*.

Part One describes my Prostate cancer experience and useful lessons learned.

Part Two is about how probabilities are used to describe prostate cancer; it is not necessary to read it but it does help inform the lessons of Part One

Disclaimers

I am not a prostate cancer expert, I simply describe my experience; for medical advice you should seek expert help.

The footnotes are to help clarify terms used in the text and are not medical definitions.

Preface

In the UK some 40,000 men are diagnosed with prostate cancer each year, it is the second main cause of death in men. For *nine out of ten* over the age of 70 the cancer grows slowly and old age and its infirmities will find something else to carry them off before the prostate cancer can do it. For the misfortunate *one in ten* the cancer is *aggressive* and without treatment they will *die from it.* The *'probability'* of dying from it is much less with early treatment *and yet* each year 11,000 men still *die from it,* mostly because they do not *find out in time* that they have an *aggressive* prostate cancer.

Without some kind of early warning, and an effective response to it by your GP, you won't *even know* that you *have* a cancer until clinical symptoms appear. If you don't know that you might have a cancer you will not, of course, take steps to find out if it is *aggressive*. A *voluntary* general screening programme for men over the age of 60 could perhaps save many lives by alerting you in time.

Much of the argument against general screening is underpinned by *statistics*. I deal with statistical interpretations in Part Two.

The cost argument says that if *nine out of ten* will die from something else it is not worth the cost of testing for it. Counter argument. If *you* are one of the misfortunate *1-in-10,* the cost is outweighed by the benefit, at least for the patient if not for the accountant.

Argument: It is *'not worthwhile'* for the NHS to carry out screening because *'most'* tests, and particularly the usual first early warning indicator of prostate-specific antigen, (PSA[1]), do not give *certain* answers. Counter argument: Little *is* certain about prostate cancer diagnosis until the later stages of the disease, but for a higher risk person that is not a good reason to do nothing when more could be usefully done. Newer and more reliable tests are coming and in any case, a sudden change in PSA[2] is a more reliable warning and enough to encourage a follow up by doing some simple tests such as a DRE[3], which is a good warning. One of the newer tests, an EPI[4] may soon become available.   Although there is no certainty about any tests, if all three tests suggest a possible cancer, the probability is higher and then a biopsy[5], or perhaps a PET, is surely a reasonable precaution to take to improve diagnosis.

Argument: A prostate-specific antigen, (PSA), does not give *certain* answers and sometimes a false one, therefore an incorrect cancer warning would unnecessarily frighten those older men who could be misdiagnosed as having a prostate cancer and we should not offer them. Counter Argument: Many men may, (*after the implications are properly explained to them),* decide that they do not want to do anything about it: if they are happy to live with the chance of being one of the 10%*,* then the choice should be theirs but it must be a choice, NOT decided for them. Some men might instead prefer to further lower the chances of death rather than to die through inaction.

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1 PSA: The most common 'early indicator' test to detect prostate cancer in those without other signs or symptoms. It is not reliable; you could have cancer and a low PSA or a high PSA and no cancer. *But* PSA Velocity, the change in PSA over time, backed by other tests may provide more reliable early indicators. *3 such tests indicating a cancer persuaded me that I had one and they were right*.

2 Some doctors believe that if PSA is regularly monitored and it suddenly jumps, that can be an indicator of a cancer; this measure is called PSA Velocity. *The jump in my PSA was a correct indicator of a prostate cancer.*

3 DRE: Insertion of the doctor's rubber glove clad finger into the rectum to feel if the prostate has a lump. It is quick, slightly uncomfortable, rather undignified and said to be more reliable than a PSA for indicating the presence of a cancer; the two together are still not certainties but *for me they were pointers to the need for further tests*. If a lump can be detected the cancer could already have grown significantly, mine had.

4 EPI: Some trials suggest that this test can significantly *reduce* the need for a biopsy. Some other media reports suggest that this test may eventually be introduced in the UK for non-invasive prostate cancer screening. It is claimed to be 95% accurate as an indicator of an aggressive cancer. Thus it does two tests in one procedure, one for detecting a prostate cancer and the second for assessing the chance that it is aggressive. *It was certainly accurate in my case*.

5 Biopsy: An undignified and slightly uncomfortable procedure to remove samples of suspicious tissue from the prostate. A needle is used to collect a number of tissue samples from the prostate gland that are studied in a laboratory. If cancerous cells are found, they can be studied further to see how quickly the cancer will spread. This is called "staging and grading" and helps doctors to decide which treatment is most appropriate. It is more certain than any of the other tests but a serious cancer can *still* be missed; *it did not miss mine.*

Part One

A Cautionary Tale

My case history

Yesterday upon the stair
I saw a man who wasn't there
He wasn't there again today
I do so wish he'd go away.

The 'man on the stair' is a possible prostate cancer, many men just wish it would go away - which is why this is a cautionary tale.

My Prostate Cancer Experience

What I did right

After reaching 50 years of age I got an annual blood profile[6] test to see if I had any early indicators of future diseases that had been responsible for the majority of early deaths in my family going back a couple of hundred years, reasoning that catching any such a disease early would give me a better chance of living longer.

Two years ago, *before any other clinical symptoms appeared,* a profile showed a jump in my PSA and thus warned of a possible prostate cancer. I had done the right thing and found out early that I *might* have a prostate cancer.

What I did wrong

I should have confirmed or diminished the '*probability'* that I had a prostate cancer with further tests, but I didn't; nor when I accidently found out that I really *did have prostate cancer* did I try to find out if it might be *aggressive*. Instead, I was persuaded by the medical response to my elevated PSA that it was "*not unusual for someone of my age and that a PSA test was unreliable"* and I trusted in the *mantra* that even if you have it *'you will 'probably' die with it not from it'*.

Beware! That mantra is a statistical interpretation <u>not</u> a medical diagnosis.

Why do many doctors not draw attention to a warning from a PSA test, or when you draw their attention to it, give the advice, *'you will 'probably' die with it not from it'*? Because it is true! At least it is *statistically* true, but *statistics* are no comfort if you subsequently find out that you are amongst the ill-fated *1-in-10* who has an aggressive prostate cancer and particularly if you find that out too late because then the *probability* becomes that you may die from it.

I was wrongly persuaded to ignore a warning signal - a sudden jump in my PSA level. If things had been left like that I would probably die from prostate cancer. I may have been saved by a lucky break:

Whilst recovering from a heart bypass operation I was visiting the USA and my blood pressure went haywire. I went to see a local doctor and she said: "Your blood pressure is fine, but you should see a urologist because your PSA has *jumped* since the last time you had it measured"; (I had sensibly taken along all my blood profile history). She it was who alerted me to the to the possible significance of such *a PSA jump*. It was surely sensible to try to confirm it? So I reluctantly went to see the USA urologist thinking that I had nothing to lose other than the cost of a consultation: Good decision, bad news. He did a digital rectal examination, (DRE, (an undignified couple of minutes procedure to feel with a finger if there is a lump in the prostate), and diagnosed a probable cancer, thus supporting the PSA warning. His was not a '*statistical <u>interpretation</u>'* it *was a diagnosis.* I had two tests and two warnings!

The urologist advised that I should have a biopsy. I did not want to suspend my post bypass operation medication, so unconvinced that I might have an aggressive cancer, I deferred having one. I did do *something* sensible, though, I paid for an MRI[7] scan**.** Good decision, bad news. That too showed that I had a tumour. Three tests, three warnings!!

What should I have done next? Confirm the possibility and find out if it was *aggressive*, but trusting in the *mantra* I decided on *watchful waiting[8]*. Delay in starting treatment for an aggressive cancer is unwise*;* I was betting on a statistic, a low *probably* that if I had a cancer it would not be *aggressive*; it was a grave mistake.

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[6] A blood sample is taken and assayed to measure the levels of key biochemical parameters of the functioning of certain organs such as the liver, kidneys, thyroid and heart, infections and certain genetic disorders, as well as to assess an individual's general health.

7 MRI, a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

8 Watchful waiting: Doing nothing except to take regular PSA tests to see if PSA was increasing which would need further confirming diagnosis

Choosing not to suspend my cardiac treatment I instead paid for an EPI. It estimated my Gleeson score[9] *as* 3+4 = 7 just above the threshold of a signal of an *aggressive* prostate cancer. A PSA alone, or even a jump in a PSA, may be unreliable *but 4 consecutive tests* with the *same tell-tale result* were starting to add up to something perhaps?

Back in the UK I again paid to be referred to a UK oncologist. Good decision. The new oncologist, like his US fellows, recommended a biopsy and *once again* I foolishly decided to *'watchfully wait'*, but asked for another MRI. That was one of the few smart things that I did. Good decision, bad news. The cancer had increased markedly in size since my last MRI, another blood test showed my PSA had also jumped again and by more than 0.7.

At last the scales fell from my eyes. 9 vital months had been lost in trusting in a *'statistical interpretation'.* I *finally did* what I should have done much earlier and had a biopsy. A biopsy is disagreeable but *will* give a fair indication that a cancer is *aggressive*. Mine was.

Probability may have indicated that *only 'one in ten'* men need to act*. I was now one of them* and I needed to act fast because so much time had been lost, time in which the cancer had grown alarmingly.

The urgent need now was to quickly determine if the cancer had *spread outside the prostate*, i.e., that it had not *metastasised.* To find out if it had metastasised I had a PET[10]. Bad news, good news; it indicated an *aggressive* T3b (locally advanced cancer). It had spread to the seminal vesicles, the 'escape route' out of the prostate to neighbouring tissue and bones and had started to penetrate the capsule surrounding the prostate; but *probably* had not yet escaped.

This tumour had its foot on the accelerator and preventing a spread *was now essential*! My oncologist recommended *immediate* hormone therapy to be followed by radical radiation treatment.

I asked what would happen if I declined hormone and radiation therapy, (which like all prostate treatments can have disagreeable side effects), and continued with '*watchful waiting'*. He said it will spread and you could be dead within a few years. Well that rather did decide things because all the alarm bells were now deafening. Did I really still stand more chance of *'being knocked down by a double decker bus'* as I had been told?

The artfulness of the *mantra* is in offering a low risk choice as naturally attractive and in such a way as to play down the penalty should it *still* happen despite the low risk. The argument is that if *most* of us will probably die of something else anyway, why undergo disagreeable tests with possible unpleasant side effects when the chances that they are necessary are so low? The answer to that is: because low chance or not, if you should be one of the unfortunates who are numbered in the *1-in-10* then you will die.

With such a high chance of survival and given the uncomfortable consequences of living for years with the knowledge that one has a cancer but not knowing if it will eventually become *aggressive*, not telling someone he has a cancer may be a kind choice. But the choice should surely be for the patient to make and not be a choice of possible euthanasia chosen by someone else?

A sad truth

Despite *the mantra* assurance of 'nothing to be concerned about' I was in mortal danger. I luckily found out, by accident, that I really did have a prostate cancer. Fortunately I then also had the resources and the opportunity to get an MRI and then further tests. There are thousands of men in the UK who will not have my luck and my advantages and who might be unaware that they have a cancer and afterwards find out, too late, that it is *aggressive. This Paper is for them.*

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9 Gleeson score: A system for grading cancerous cells which fall into 5 distinct patterns as they change from normal cells to tumour cells. The cells are graded on a scale of 1 to 5. Grade 1 cells resemble normal prostate tissue. Cells closest to 5 are considered "high-grade" and have mutated. This grading is usually carried out following a biopsy. Like all tests, it is not 100% certain, serious cancers can still be missed

10 PET: The injection of a radioactive isotope into the prostate, which attaches itself to cancerous cells and shows their spread through a scan.

Lessons that I learned which could be useful

1) Don't play Russian roulette. The *probability* of blowing your brains out is only a modest one in six, but no sensible person takes such a modest chance if the consequences of a bad break are so catastrophic. Taking the bet that you are in the *'nine in of ten'* <u>is</u> playing Russian roulette. The chances that you will survive are comfortingly high but the consequences should you make a bad bet are catastrophic. If you have a warning that you might have a cancer, take steps to either confirm or to reduce that possibility by having further tests and if you *do* seem to have one, find out if it is *aggressive* without wasting time.

2) More reliable tests are in the pipeline but until they are introduced a jump in PSA can be a useful, if not certain, first cancer warning. As a first line of defence you cannot be worse off by using it and it is better than waiting until clinical symptoms appear. If you have a cancer and a PSA misses it, you have lost nothing, because you are no worse off. If instead, it says that you may have a cancer then being frightened for a little while before more tests say that is unlikely seems a small price to pay for playing safe.

3) You cannot reduce the *probability* of having prostate cancer, nor, if you have one, the *probability* that it may be *aggressive*; but you CAN do something to improve the *probability* that you will die of something else by detecting it early and having treatment *in time* - and the choice should be yours.

Conclusion

The jump in my PSA was dismissed using a misleading mantra; through other sufferers I realised that its use is so common that I suspect that a doctor's response is not a reasoned diagnosis but is something institutional. The NHS should *stop* presenting a statistic as a diagnosis. Permitting the 'auto-response' of "you are *probably likely to die with it rather than from it"* is essentially a statement that no further action is planned; that is misleading because it persuades the unknowing patient to accept that verdict and in 10% of cases that could be fatal. The choice should be consensual, *how happy are you to live with maybe being one of the 10%?*

The NHS should also usefully consider offering *voluntary* general prostate cancer screening from 60 years of age, or earlier for those with a family history of it.

Epilogue

Will the hormone and radiation treatment succeed for me?

It *probably* will - as long as I started the treatment in time; who knows?

I am convinced that:

1) Had I not been wrongly *persuaded* by the 'mantra' to discount my suddenly elevated PSA and if...

2) I had had further simple tests to support or disprove that first warning and if...

3) I had had a biopsy or another more certain test *as soon as I knew* that a cancer was *probably* present and started the treatment when it was shown to be aggressive....

The *probability* of a successful outcome would have been higher.

Note: I have described only my experience and treatment. There are a lot or different treatments amongst which are 'watchful waiting', prostatectomy, brachytherapy, hormones and radiation. Your experience will probably be different to mine but the common issues are the way probabilities can be presented as diagnosis that encourage complacency and delays early diagnosis. It is sensible to inform yourself as best you can of your condition and to try to understand the language in which probabilities are expressed to help you make a more informed choice with your physician. Read on....

Part Two

Probabilities and their role in diagnosing Prostate Cancer

There are lies, damned lies and statistics

Why statistics and probabilities figure in diagnosing Prostate Cancer

There is no *certainty* in most of the tests for the presence of prostate cancer, nor is there certainty in determining if a prostate cancer is *aggressive,* so the results of tests are rightly presented as *probabilities* using terms such as: 'maybe', 'might have', 'could be', 'chances are', etc.

Probabilities are just a way of interpreting a *statistic.* In my narrative the relevant *statistic* is the measure of the usual number of deaths in men aged over the age of 70 who have a prostate cancer who will die because of it - as it happens, one in ten of them.

A statistic is usually expressed as a percentage chance of something happening, but when it is further confidently explained as by 'that mantra' it may be statistically correct but it encourages inaction that could lead to death. My own experience related in Part one is a good illustration of how it can influence such a response.

How you can draw different conclusions from the same statistical truth

Equally valid but different *presentations* of the *same statistic* can influence a patient's understanding of his condition.

As a suitable example consider: When aged over 70, of those men *who have* a prostate cancer:

> '*9 out of 10 will probably die with it, <u>not</u> from it'.*

Or:

> '*1-in-10 'will probably die <u>from</u> it'.*

Both presentations are equally valid, yet being told that you stand a *'one-in-ten'* chance of *dying from it* might change your reaction from complacency, (encouraged by the mantra: '*You will probably die with it, not from it',* way of presenting that statistic), to a desire to act to further reduce the low *probability* of death, by getting treatment in time.

Whilst it may be *statistically* true that there is a *9-in-10* chance that your cancer will not kill you, that *presentation* does <u>not</u> say whether <u>YOU PERSONALLY</u> are *included* in *9-in-10.* The statistic just says that you have a 90% chance of dying from something else. It sounds good and it *is good*, but telling a patient that '*You will probably die with it not from it'* is better more likely to be right if further tests do not suggest an *aggressive* cancer.

This would be more balanced presentation: **"The test is not that reliable, but it shows a possible prostate cancer. We could do a few more different tests to see if they agree, but don't worry, even if they show that you might have one, as only 10% are aggressive at your age, you are more likely to die of something else. If you are not comfortable to live with 10% chance of it being aggressive, there are other different tests to check that out and then early treatment is usually very effective.**

Getting informed

The more you know about prostate cancer the more it will help you to understand what the professionals are telling you. It helped me to realise that the initial advice that I was given could lead to an early death and to seek more accurate advice.

There are hundreds of published research papers articles, Internet pages and promotions from clinics on the subject. I read a lot of these and additionally 5 books on the subject. All 5 books were useful and broadly consistent. I found the most useful was by a US oncologist/urologist in this field who was himself diagnosed with the condition (and at quite a young age, relatively speaking). The book is aptly called 'The Decision' and is by Dr. John McHugh. I found his approach to the unwelcome indications of a cancer and his criteria for deciding what he would do and which treatment he would select to be very useful. I did not use the same criteria because my age, diagnosis and available treatments were different to his, but his logical, analytical and informed approach seemed sensible to me and I adopted it.

I just wish that I had adopted it earlier.