

Breast cancer: When do you stop reading the literature?

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Science and research consume a substantial – some might say the greater part – of my life. It is an all-consuming passion that many fail to understand. Professionally, I divide my time between managing a substantial research programme and running what is arguably the largest science faculty in South Africa, if not the continent. I am not only passionate about my research but also about sharing this passion with others, particularly young researchers, and I believe I am good at what I do.

A year ago, and perhaps reluctantly given many other responsibilities, I arranged for one of my least enjoyable responsibilities – an annual mammogram. This year my visit took a bit longer than usual because the radiologist found a mass ‘he did not like’ and that required a biopsy. At this point I did not give the situation much further thought. A week later I received a phone call to inform me that I had cancer. This phone call was the start of a very frustrating period in my life; perhaps ironically made especially difficult for me because of my research training. It heralded a time at which I entered a world both foreign and frightening – that of being a cancer patient.

As a scientist, my life follows a very logical route and one that is largely based on evidence. I have been trained to ask strong questions and to test hypotheses that might lead to answers; this process is the central core of my professional life and I debate everything, even with myself. This philosophy inevitably spills over into my personal life. My first approach to any problem is to read and understand the literature and to then make decisions based on available evidence. I am sure that this approach resonates with most scientists; it is after all what we say in our conversations with our graduate students: ‘One cannot embark on any project until one has read the relevant literature.’ I thus entered the world of being a cancer patient in the same manner: I started reading the appropriate literature.

I read first to understand my diagnosis and then to try to determine what might be a reasonable treatment. Initially what I read seemed completely logical; but the more I read the less logical it all became. The scientific literature, while encompassing many details that serve to explain some of the key issues, is also crammed with statistics. And therein I encountered one of my greatest frustrations: it was not possible to know which statistic I represented. Was I one of the very small percentage that is unlucky and would have a recurrence of the cancer? Or one of those representing a much larger percentage who will live a long life in the absence of such a recurrence?

As I delved further into the literature concerning breast cancer diagnoses and treatments, I was reminded rapidly that statistics are useful when one is conducting research but they are not particularly helpful when you yourself are one of those statistics. As a scientist I rely on probability testing for many decisions. Thus it was incredibly difficult for me to encounter a part of my life in which statistics were not particularly helpful. In terms of reaching decisions based on clearly understanding my diagnosis, I found that my training in science had failed me. It may well be that my science-based world is inordinately black and white.

Reading the literature on breast cancer and its treatment highlighted for me the fact that in many respects these aspects represent a debate – one that is clearly ongoing, which is perhaps not surprising when I think of my own research exploits. But it quickly became evident to me that for many of my questions relating to breast cancer there are no clear answers. I realised that it is one thing to do research oneself and to be part of the debate, in which someone will eventually reach an acceptable answer, but another thing to be stuck in a moment in time when one desires a clear answer immediately but learns from the literature that there is no consensus. It is a situation that is nothing less than confusing and frustrating.

As a scientist, one’s training is to read the literature and then, at that edge of the unknown, to design experiments to answer key questions. Essentially being part of what must be a larger ongoing experiment is a very uneasy place in which to find oneself. I realised that, concerning my own diagnosis, it would be much more comfortable to know very little, to blindly believe the views of the medical profession and to simply accept whatever advice they were able to provide. Subsequent to my diagnosis, I have engaged in discussions with other scientists who have cancer. Some simply have stopped reading the literature because they felt that it only added to what is already an emotionally and physically difficult situation. Interestingly, some of my colleagues have given me exactly this advice: ‘accept and hope’. To do so would be contrary to my background and nature and I have not been able to follow such a route; in fact, I have found myself reading increasingly more regarding breast cancer and the treatment options.

My family, a supportive scientist husband and two great children, have told me that they perceive me as having embarked on a second PhD – on breast cancer and its treatment. I have trained 40 PhD students during my research career and I have a clear understanding of how one should best pursue the process of interrogating the literature for a PhD: read and understand what is known, and only then is it possible to determine the gaps in knowledge to then formulate questions that can be answered. In terms of my own diagnosis, this approach has been patently without value. I have to admit that I have at times thought seriously about whether I should not be considering undertaking some research on my own tumour. I certainly have the professional skills to do a number of very interesting experiments. For example, it would be possible to determine whether the tumour was over- or underexpressing a range of genes. I am also very conscious of the fact that some of the experiments that I would consider doing will probably become standard practice within the next 5 years. Again, because of my profession as a molecular geneticist, I know more than the average patient. In contrast to those patients, this knowledge means

that I cannot fail to become preoccupied with the many possibilities that would make the decisions that I need to make regarding long-term diagnosis so much easier.

The frustrations that I have experienced regarding my diagnosis of breast cancer and its treatment are not limited to cell biologists and those people that understand genetics. In the waiting room of the radiation oncology practice where I received treatment, I entered into a conversation with a geologist, one who I happen to know professionally. His preoccupation with the treatment he was receiving was more in regard to the impact of the radiation itself, rather than the genes that I was considering. He suggested that the treatment of cancer using radiation might be thought of as a blunderbuss approach to the problem. I thus have come to believe that scientists who are faced with a diagnosis of cancer are likely to become preoccupied with that aspect of their diagnosis and treatment that is most closely linked to their own area of expertise, which makes me think of the saying 'give a man a hammer and he will find a nail'. Central to our training as scientists is the search for answers, and, in the case of cancer but perhaps all of biology, this search clearly remains a work in progress. My difficulty (which I am sure is true of other scientists too) is having to accept this fact outside of my own laboratory and concerning my own body.

As a scientist and researcher, I have learned to debate and discuss all possible options based on available evidence. When this evidence does not exist, one then proceeds to design experiments to provide the needed evidence. This is clearly not how medicine is practised. At some level, I feel some sympathy for the medical professionals who have had to deal with me. I must guess that most do not have the difficult experience of encountering a patient bearing files packed with the latest literature. In some way, even medical specialists are 'body mechanics' that must perform to some predetermined standard operating procedures. These procedures probably change over time and as new discoveries are made, but they seldom can be sufficiently up to date with the most recent scientific literature. One of my challenges has thus been to decide whether I should challenge the medical professionals treating me when I know that some of the procedures recommended are not necessarily up to date. I suppose that it is unrealistic to expect that the average specialist is reading the latest literature and applying it to their clinical practice. And I am sure that those specialists in private practice do not have access to the scope of literature that I am used to and expect to interrogate in my professional life.

As I have dealt with my breast cancer, I have found myself in a rather uncomfortable space between the reality of my condition, which needs to be dealt with, and my need to understand exactly what is wrong with me in scientific terms. I have discovered that the gap between what the medical profession understands and what I would like to understand is rather wide. This statement does not reflect negatively on the medical profession but rather highlights the fact that, despite huge leaps in knowledge, there is a vast amount regarding cancer that we do not fully understand, and certainly not at the level at which I desire understanding.

This period of my life dealing with breast cancer has been focused on making decisions about treatment, but it has also been a period in which I have *painfully* realised that it is not possible to make these decisions based on evidence. The first decision I had to make was whether I should have the 'mass', a potential tumour, removed. The medical opinion on this was clear: 'cut it out'. As I delved increasingly deeper into the literature, I became increasingly less convinced that this suggestion was in itself as clear as I was led to believe. The biopsy indicated that my cancer was slow growing, and if I had not had the mammogram I likely would not have noticed it at all; there was no lump, there were no symptoms and there was no other indication of a problem. In fact, based on the literature that I have consumed, I am not sure that my decision to have the mass removed was actually the correct one. The medical advice that I had received was overwhelmingly in favour of removal and I followed that advice. Not unimportantly, I was also financially able to afford the operation, and other than the obvious inconvenience and pain that accompanies surgery, undergoing the procedure was not too difficult.

After undergoing the operation and receiving a diagnosis on the tumour itself, the situation became a bit clearer. Yet the way forward seemed even less obvious than it had before. My tumour was very slow growing, as had been previously diagnosed. The entire tumour had been removed and the lymph glands that had also been removed were clear of cancer. This was good news, but it also meant that the decisions associated with the way forward were not so obvious, at least to me. It was at this time that I embarked upon an even more serious reading of the scientific literature. With my background in genetics and biochemistry, I could easily understand the medical literature despite the fact that I do not usually read it; my reading largely being focused on the genetics of fungal pathogens of trees.

I understand genetics and because I work in a genetics department I have a general idea of the latest breakthroughs in human genetics. In terms of breast cancer, the *brca1* and *brca2* genes have featured significantly. I was aware of the fact that these genes account for a very low percentage of the breast cancer cases that are diagnosed. I also know – because I have exposed my own genome to analysis using the million SNP markers – that I do not have either of these variants. What was rather alarming was that none of the medical specialists I encountered was at all interested in my knowledge of genetics or what I knew about my own genome. The surgeon who operated on me was more interested in cutting out the tumour and the oncologist was more interested in treating me post-surgery than discussing information from my own genome analysis. Not surprisingly, this lack of interest did not make my decisions any easier.

I have found in my recent interaction with the medical profession, and I add here that I have close friends in this field, that there is a requirement that patients sign forms at every turn, confirming that they consent to the various procedures that will be followed. I can understand that this requirement is important from an ethical point of view and I support the approach. What I am not so sure about is the concept of 'informed consent'. I certainly had a rather circular discussion with one of the medical professionals treating me before he finally stated that he needed to have my informed consent. My reaction was that he had my consent, but while he had 'informed' me as far as he could, I did not believe that I, and less likely other patients, understood enough to be making a decision based on 'informed consent'.

It might be argued that we live in an age in which we have an inordinate amount of information available to us (even whilst convalescing). I thus found myself in a rather circular manner, reading the scientific literature and then resorting to the 'lay' literature. Neither were that satisfying; the former because I could not derive the answers I needed and the latter because there were too many generalisations. My 'pet peeve' has become the common statement 'radiation kills cancer cells'. Well actually radiation kills all cells, and most often cells that are dividing are more sensitive to radiation. It is true that cancer cells on average divide more rapidly than many (but not all) other cells in the body. These generalisations, which also are very misleading, irritated me. I understand that their purpose is to simplify matters and to enable easier understanding for the general public. But I am not the general public and I know too much to feel appeased. This irritation sent me back to the scientific literature, which still contained inordinately few answers.

The decisions that I needed to make post-surgery – clearly underpinned by 'informed consent' – were to agree to radiation therapy and, because my tumour was oestrogen receptor positive, to consider taking an oestrogen blocker. I have already mentioned my sentiments regarding radiation – in my opinion, using the words therapy and radiation in the same sentence is oxymoronic. But I needed to overcome this viewpoint and to engage in a sensible discussion on the topic. The current literature, while extensive, seems only to cover the 5–10-year horizon. I would like to live longer than this time frame. In order to make this decision, I spent a considerable time reading, discussing and eventually debating the issue with a pleasingly accommodating oncologist. The average cancer patient will do exactly what their doctor suggests. The average scientist needs evidence, which in this case was not really available. I took a very long time to make my decision and in the end actually took a rather cynical approach. What I did was to leave the decision to my

medical aid. I reasoned that if the medical aid was prepared to pay for the treatment I would accept it. I realise that this decision was based on a flawed argument; the decisions of medical aid schemes are based on statistics and one cannot really know which data point one represents in this process.

My journey with cancer has only just started. I sincerely do not wish to repeat the last year of my life. I also am hoping that the next few years

will not involve making quite as many impossible decisions as those that I recently have had to face. All indications (and comfortingly the view of a friend who is also a physician and medical scientist) are that I am unlikely to die from my cancer. Of course one doesn't actually know this for sure until one has died – from another cause. I suspect that I will continue to read the scientific literature on breast cancer in addition to the other scientific literature that I read. I will not be submitting my 'second PhD' for examination, partly because it will never be complete.

