Reacting to the diagnosis of prostate cancer: patient learning in a community of practice

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Abstract

The diagnosis of prostate cancer brings with it a number of emotional issues for the patient. These may include: fear of cancer; confronting one’s own mortality; quality of life issues such as incontinence and impotence; and the question “why me?” In addition, there is burden of coping with the emotional responses from friends and loved ones which, arising from their concern, can range from fear to seeking to take charge. Added to this is the need to make choices regarding treatment and obtaining information about these. This article is based on a contribution to a symposium on prostate cancer at the Fifth International Conference on Psycho-Oncology and describes a personal experience of confronting these issues. The concept of communities of practice is used to interpret the learning experiences undertaken by the cancer patient.

Keywords: Patient education; Communities of practice; Prostate cancer

1. Introduction

At age 52, I went to my general practitioner and asked for a check up—heart, lungs, stick out your tongue, stethoscope and all that. I see him fairly regularly as he keeps a close watch on my blood pressure and cholesterol levels, stitches up my head when the boom of my sailing dinghy catches me unawares, and has a looked after my family for over 20 years. However, it had been quite some time since I had a thorough check up. Part of that was a digital rectal examination (DRE), and I can still remember the way that he slumped into his chair and pronounced the words “It is a bit enlarged on one side, we had better have a blood test”.

That started me on a journey and my wish is to tell you something of that journey, not as a journey of population averages, but as a story. For it is through stories and the telling of stories that “world making practices”, that the ways of understanding our world become possible [1]. Stories are not histories, although the Medical History of my journey is included below, for stories and narrative processes give recognition to a world that is not fixed on population means and measures of central tendency, but a world that is negotiable, which exposes relationships, gives meaning to experience and identity to the practitioner.

I had a number of advantages in this journey:

- firstly I had excellent medical practitioners who were more than willing to provide me with information;
- secondly, I was a former medical research scientist who had spent 20 years researching anti-cancer drugs, so I could understand the literature, but more importantly I had a network of former colleagues from whom I could obtain information; and
- thirdly, I had ability to use the Internet and email to link up with hundreds of people receiving similar therapy across the world, so protocols, treatment technology, patient care techniques, side effects, etc., were compared.

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Medical History

The 52-year-old patient presented following a routine medical examination that indicated an enlargement on the left side of the prostate gland. Subsequent blood analysis had revealed a slightly elevated Prostate Specific Antigen (PSA) of 6.0 ng/ml. Ultrasound guided needle biopsy had indicated two out of six samples were positive with a Gleason score of $5 + 4 = 9$. The initial clinical stage was T2b.

The bone scan was negative but the CT scan indicated possible enlargement of the median lobe of the gland. Subsequent rectal ultrasound indicated that this was an artefact but suggested there might be bowel wall involvement.

The patient was placed on adjuvant hormone therapy, Zolodex\textsuperscript{TM}, for 3 months, at which stage a repeat transrectal ultrasound indicated no bowel wall involvement and the patient was judged suitable for brachytherapy.

A protocol of neo-adjuvant hormone therapy, Zolodex\textsuperscript{TM}, external beam radiotherapy for four and a half weeks ($2\text{ Gy} \times 23$), followed by $16\text{ Gy}$ high-dose rate brachytherapy was delivered. The patient tolerated the treatment well with few side effects and has not experienced incontinence or impotence. Eighteen months after cessation of treatment the patient remains well. PSA measurements taken at three monthly intervals in the 18 months following treatment have remained stable at 0.4 ng/ml.

It does not say that I was not afraid. Cancer is confronting, it does have the habit of forcing you to face up to your mortality, it did cause some moments of introspection, but like Dylan Thomas \cite{2}, I had no intention to “go gentle into that good night”.

2. Diagnosis

The diagnostic procedures for prostate cancer are fairly confronting—you rapidly learn that a DRE has nothing to do with computers. Some examiners are quite gentle, some feel as if they have just come in from mixing concrete, and you wonder whether some are using their elbow. It is a time when you feel violated physically and emotionally by people and equipment. When you rapidly become the non-person who goes from one diagnostic machine to another. The typical female response of “now you know what we experience”, just does not help.

It is also a time when you are on a steep learning curve. Not only do decisions have to be made but you have to come to grips with new language, new terminology and new meanings. For example, the Prostate Specific Antigen test measures the blood levels of a substance that is normally secreted by the prostate, but which is elevated by a number of factors including the presence of cancer. A level of greater than 4 ng/ml is of concern. Similarly a Gleason score is a measure as to how aggressive the tumour is, or how different the cells are from normal prostate cells. On a scale of 1–10, a score of 9 meant that I had a fairly aggressive form of the cancer. Staging of the tumour in my case was T2b which meant that the cancer was palpable and involved half of one lobe of the gland. It is also when you are confronted with different treatment choices, surgery or radiotherapy, and then different types of radiotherapy such as seed implant brachytherapy or high-dose rate brachytherapy. There are two types of brachytherapy performed for prostate cancer. With seed implant brachytherapy, radioactive seeds, usually an isotope of iodine or palladium, are implanted into the prostate and left to decay naturally over a period of several months. In high-dose rate brachytherapy, thin tubes are inserted into the prostate and left there for a period of approximately 36 h during which the patient will be connected four times to a machine which inserts a highly radioactive pellet of iridium through the tubes and into the prostate for an accurately determined time. In both forms of brachytherapy the aim is to deliver the radiation direct to the tumour.

You begin to learn about the possible side effects and consider the longer term implications of incontinence and impotence. All of these contribute to the turbulent journey you have just made from being a supposedly healthy person to a cancer patient.

It is the time that you are dealing with your emotions, your partners and family’s emotions, and the emotions of your friends. For me, immediate family was relatively straightforward, their responses were predictable, after all we had been together for a long time. Extended family was more difficult and the elderly aunts in their late 80s still do not know. Acquaintances such as work colleagues, or fellow sailors were fairly straightforward. A lot of the males went off and had tests themselves or were hounded into it by their partners. The biggest problem with some acquaintances was that they wanted to meddle, or they assumed they had a right to offer such things as pastoral care, advice, diets, alternative treatments, etc. The constant reminder of how well one looked or how brave one was being got a bit tedious after a while. Friends were more difficult and coping with their emotions was the “double whammy”. After a number close friends telephoned, or visited in tears, one’s reaction was to avoid telling them, simply so you did not have to cope with their feelings. One good friend I did not tell until it was all over as I just could not cope with her feelings. In some ways this could be interpreted as a desire to protect people whom one would classify as close confidantes.

Other friends helped me cope in different ways. One gave me permission to be angry if I wanted to be. Another, who had rung up in tears when she learnt, gave me a big hug in front of a group of good mates and asked how all my ‘dangly bits’ were, giving me permission to talk about what was happening and how I felt about it. Another, to whom I had
emailed about the perils of being irradiated with a full bladder and having the machine break down, broadcast my comments far and wide, giving me the permission to use humour as a means of coping.

3. Feelings

The feeling of many prostate cancer patients is summed up for me in the words of McKenzie [3], the editor the Education Technology Journal:

One of the surprising aspects of the prostate experience for me was the relative silence in the literature regarding the emotional and psychological aspects of this disease and experience. I found the medical information unfortunately focused primarily on the physical survival aspects and was quite upset to note a “grin and bear it” attitude toward some very important issues such as impotence and incontinence.

Now that I am 3.25 years past treatment (authors amendment) and have a <0.1 PSA, I can see that the psychological impact is pretty serious and yet there is little treatment offered or provided. There is usually not even the hint of speaking with a therapist or social worker about relationship issues and fear issues. Unfortunately, a primarily medical model is applied to what is far more than a physical situation.

For example, I think that my sense of longevity was dramatically disrupted when diagnosed at age 51. I felt like I’d been robbed of my old age. This robbery had the deepest and gravest impact on my dreams and my ability to plan for the long term. I became especially committed to seizing the day. As a writer and thinker I began to feel my days of work and thinking might be cut short.

Even though I read volumes on prostate cancer, I saw little to help with these issues. I had to find my own path without much help from professional others. My wife and friends became essential partners in this search for understanding.

Three years later I have gradually been able to regain a sense of longevity, thinking that I might just be cussed enough to endure for 25–30 years. Not so long ago I was afraid to put much stock in that belief. I was sort of crouched in a defensive posture, knowing that cancer may recur for no apparent reason just when you least expect it. I was taking a “low expectation” stance to avoid tempting Fate. Now I have moved to a stronger position.

4. Information search

Another interesting aspect of my behaviour, was my information search, and there were three distinct phases to this:

- from initial to confirmatory diagnosis, that is, DRE to biopsy result;
- from diagnosis to treatment choice; and
- then following treatment choice, a confirmatory search.

As an academic I had access from my desktop computer to the full range of medical journals, in full text. As a former cancer researcher I had the technical knowledge to understand those articles. I had always believed that if I had cancer, the first thing I would do would be to visit the medical library. Yet I did not. I knew from the initial diagnosis and PSA test that there was a high probability that I had prostate cancer, yet I did nothing until I had that telephone call from my urologist to say that the biopsy was positive. Did I hit the literature—NO! What I did was hit the network. Any source of verbal information from people I knew I could trust, regarding treatment options, side effects, who were the best practitioners and the most appropriate treatment. In effect, I re-entered a previous ‘community of practice’ [4–6]. So 3 days later, when I had my second appointment with my urologist, I had a preferred treatment, a preferred practitioner, and even a copy of a treatment protocol. Fortunately, my urologist went through all the options, the advantages and disadvantages, took into account my lifestyle and made a recommendation that was identical to the decision I already had made. Then came the third phase of information search, after I had seen the specialist to whom I had been referred, when I went to the journals, the Internet and the Internet-based support group. That was when I joined another community of practice, one of other patients comparing notes, information, emotions and feelings. It was with this community that I understood the significance of the new terminology and the meaning attached to that information.

5. Support groups as a community of practice

Lave and Wenger’s concept of a community of practice [4–6] has already been mentioned and this framework can be used to explore my feelings and emotions as a prostate cancer patient. Some might say that initially I had simply used my network. That is correct, but it was more than that as Wenger and Snyder [6] discuss:

A network is a collection of friends and business who pass on information that meets mutual needs and exists as long as people have a reason to connect, whereas a community of practice goes beyond that, in that it consists of members who select themselves, who have a passion for and a commitment to the groups expertise, who develop members capabilities to build and exchange knowledge and who belong as long as there is an interest in belonging.

5.1. Practice as a patient

Where does the patient obtain meaning and identity as they are confronted with the reality of diagnosis of cancer.
They become a part of one community of practice that consists of medical practitioners, specialists, nurses, technicians and all the other people who are mobilised to impact the patient. That community identifies the person as a patient, but does not provide the patient with identity. If anything, it acts to de-identify the patient. The patient’s participation becomes reified into words in a history, images on celluloid, figures on a chart and the terminology of medicine. This is quite right and proper; it is the process science as applied to ensuring the best outcome for the patient. It also performs the valuable function of allowing all of those practitioners to do their job for all their patients.

They find meaning from the reification of the patients participation and their own participation in their community of practice.

However, is that the only community in which the patients learns their practice of ‘patientry’, in which they explore their new identity as a cancer patient and attach meaning to their practice identity, emotions, feelings and belonging?

5.2. Meaning

In this context we are using meaning not in some philosophical or metaphysical sense, but in the sense of the meaningfulness to the patient [5] of the experiences in which they are participating. This practice as a patient includes not only the participation and reification but all those elements of medical procedures, social interactions, language, terminology, with which the patient engages and out of which they negotiate meaning. To give an example: I had been through all the pre-treatment procedures, CT scans, bone scans, ultrasounds that always seemed to involve stripping off, getting into a backless gown, several sizes too small, with non functioning Velcro, or ties, and going along corridors clutching my clothing which always seemed to drip along behind me. Then daily radiotherapy started and I was presented with a gown that was a decent size, front opening like a bath robe so I could wrap it around myself, and a pigeon hole with my name on it in which to store it between treatments. I could make the transition from being the Ian who arrived at the hospital in clothing that represented me, to the Ian the patient lying semi-naked under a large machine surrounded by technology, in a way that provided me with comfort, dignity and a sense that it was still me. It gave me an identity, a sense of belonging, and some meaningfulness to my experiences.

5.3. Support groups as a community of practice

My wife and I are not the type of people who belong to groups. To us the concept of a support group does not belong. It does not mean that we are self-sufficient or do not need support. At times of trauma in our lives, various people have suggested support groups and the idea of sitting in a room with a group of people discussing our situation is not us. At various times of trauma we have received support and given support to others, but this has been with a collection of individuals not a formal group. We are not the personality types who seek support [7].

That is not to say that we do not see support groups as positive. After all, prostate cancer is one of those stigmatising diseases that studies have shown have the highest support seeking behaviour [8], but the support I found came through a community of practice rather than a formal group. That community of practice existed as an email list server, associated with a prostate cancer web site. If I sent an email to the site, about 400 others around the world received it, and I received theirs. In addition there could be, and were, private emails that went between individuals. They shared experiences, technical and emotional, protocols and procedures, knowledge and information. It was a group that was helpful, empathetic, and supportive, uncritical and used significant self-disclosure, not unlike that found by Pistrang and Barker [9] in their study of fellow patient support of breast cancer patients.

It was, and still is, a community in which I could learn my patienty, in which I could negotiate meaning and claim my new identity as a cancer patient.

In this community, whilst my participation was reified as archived emails, the meaning learning and identity came out of my participation, and it was meaning for me, not for someone else. My responses may have provided meaning for others, but that resulted from their participation.

It was a coherent community conforming to the three dimensions of: mutual engagement; joint enterprise and shared repertoire that define a community of practice [5].

The mutual engagement was between a diverse group of people who had undergone, were undergoing, or were considering undergoing a particular type of treatment. That and the ability to send an email in English are the only things in common. There is a huge diversity of political belief, culture, personality and need, education and speciality, yet they form a coherent group whose contributions are complementary. Like any community it has it’s tensions and conflicts, yet it is a community of openness, frankness and support.

It is a joint enterprise in that there is no formal membership, structure or hierarchy. People drop in and drop out, they negotiate their meaning and their responses to their situation and there is a sense of mutual accountability. Information of doubtful veracity is challenged, procedures are questioned, people refine their knowledge and learning by constant negotiation, there are no ‘gurus’.

It has a shared repertoire of words, stories, histories and symbols that have evolved to become part of the practice of the community. There is a library of personal stories that are part of the history, there are the standard emails sent to any newcomer, there are the email shorthand acronyms that belong to the community which the newcomer learns. Yet, this repertoire, as well as reflecting the history of mutual engagement, also retain inherent ambiguity, that allow for the negotiation of personal meaning for the participant [5].
The repertoire becomes a resource by which the participant can negotiate their meaning, find their identity and learn their practice.

5.4. Boundaries and constellations of practice

So, I, like many other patients, spanned the boundaries between different communities of practice:

- The formal medical community of practice in which my participation became reified, that reification providing meaning about me, but not for me.
- The community of patients with whom I corresponded and negotiated meaning, learning and identity.
- The community of family and friends who provided emotional support and care in which my identity was not as a cancer patient.
- The other communities, such as work and sailing, where my identity as a cancer patient was peripheral, but in which it still impacted.

The first community was one of formal information. Although there are studies that highlight perceptions of lack of information exchange from practitioner to patient [10], or specialty biases within that information [11], that was not my experience. I was provided with any information I sought and was offered information I did not realise I would need. Even the nurses on the ward the evening before I underwent brachytherapy were eager to ensure I understand the techniques of what was to happen. However, this information supply was limited by three factors. The first being that I often did not know the questions to ask, and the second being the limited time spent with the members of this community. From diagnosis to end of treatment was 6 months. In that time I saw my GP three times, my urologist twice and my radiation oncologist maybe 12 times. I interacted with technical staff during radiotherapy and diagnostic procedures, with nurses on the ward. The total time maybe would add up to a full day in 6 months, and at predetermined times. The third is that the information was to a greater extent formal and technical.

In the second community, I learnt the questions to ask, received formal and informal information and information that often had an emotional context. Like Ron who revealed in a private email that he was frightened of having patient-controlled morphine as he had been a heroin addict many years previously. To this community I could reveal my emotions, I could mask them in humour, I could be frank, I could be obtuse, I could negotiate meaning and learning.

The third community provided me with the hugs.

5.5. Community of practice versus consumerism

It is customary these days to see the patient as a consumer, so that health care is some sort of economic good to be traded [12] or customer, in which the patient is transformed into having an ongoing commercial relationship with an organisation. Such views not only pervade the health sector but other similar areas such as education [13,14]. Such analogies, drawn from economic concepts of production and consumption, do little to address the learning, meaning and identity associated with becoming a cancer patient. They do not extend to dealing with the emotional and psychological aspects of a diagnosis of cancer. Nor do they extend to encompassing the relationships that develop as the patient participates in the medical community of practice. They do have limited value, for example, being presented with a bill while you are still wearing a backless gown following your biopsy and told to ‘pay it on your way out’, is not good customer service in any business, but that is a very constrained view. However, they are not consistent with patient surveys such as the one conducted by Nair [15] or Wing [16], that indicate that the vast majority of people prefer to be called “patient” in health care settings, over other terms such as ‘customer’ or ‘client’.

So we can contrast the economically based “consumer view”, with a view that encompasses emotions, feelings and relationships, through patient participation in multiple communities of practice.

6. Conclusion

The stanza from TS Eliot’s poem “The Love Song of J. Alfred Prufrock” [17]:

I have seen the moment of my greatness flicker,
And I have seen the eternal Footman hold my coat and snicker,
And in short, I was afraid.

summed up my feelings at the end of my treatment—it leapt out of the page as I read it up on ward the morning I was to be discharged after completion of my brachytherapy.

Fear is something that all patients have. I rarely admitted it but I was just as afraid as the next person, but I retained control because of four factors.

The first was my confidence in the medical community of practice. Not a blind confidence but an informed confidence, informed by the other factors.

The second was my ability to obtain and understand information; I could access the medical literature, read 10-year outcome reports, become acquainted with Gleason scores, cancer staging and access the Parton Tables. This provided me with technical knowledge.

The third was my participation in a community of practice, to link up with hundreds of people receiving similar therapy across the world. This provided meaning and identity, and learning.

The final one was my community of family and friends, who teased me, cajoled me, gave me permission to be angry, supported me and cared for me.
To sum up, I cannot say it was a positive experience, cancer is not and it is one that I could have done without. But to quote McKenzie again “It has inspired some very deep thinking and given birth to some important resolutions. While I would never wish it on anyone, I have learned to make room in my life for its shadow . . . a small room, as it turns out . . . not the primary wing of my house which is reserved for the sun.” [3] It has been a learning experience, and I have been touched by some wonderful people.

I have seen the eternal Footman hold my coat and snicker, but I have stared the Footman down for now.

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