Doctor–patient communication: learning from patient experience to improve services

Dr Eric Watts practised as a GP in Clapham and Canada before specialising in haematology as a consultant, and later spent ten years as clinical director of Basildon Hospital. Now retired, he continues to campaign for better communication between doctors and patients. Here he details his experiences, from his many perspectives: as a teenage cancer patient in the 1960s, as a doctor-in-training and later consultant, and now as an advocate for improving patient–doctor communication.

The doctor–patient relationship has changed greatly over the last 60 years, especially with respect to childhood and adolescent cancers. The many reasons include improved prognosis with modern treatment, a less deferential society and a growing awareness of the value of patient empowerment. While progress has been made, we still need to make progress in how we manage patients through treatment, and after the difficulties that follow.

Survivors should not have to see themselves as anything other than people who have been dealt a dose of particularly bad luck, but all too often their confidence is diminished (albeit inadvertently) by health professionals undermining them through underestimating their coping skills.

It is now recognised that patients surviving cancer may face long-term issues in returning to their previous 'normal' lives, a journey termed the 'survivorship agenda' by Ciarán Devane when he was chief executive at Macmillan. This is becoming ever more important as more younger patients survive treatment, and go on to live longer than the average cancer patient.

How doctors speak to patients has a profound influence on how patients view not only their illnesses, but themselves too. I do not think this point has been made well enough in communication teaching, which often concentrates on how to handle one consultation – with the implication that the job has then been done. My experience illustrates that serious illness requires medical professionals to frame the communication process as a long-term relationship that develops between doctor and patient.

My early teens as a cancer patient

In 1960, aged 12, I had a paravertebral neuroblastoma requiring months of inpatient treatments followed by pulmonary metastases two years later. As was normal at the time, I was told nothing, other than to lie still and endure the treatment.[1]

As I had previously been in severe pain and this was easing off I was not too worried at the outset, but as time wore on I naturally wondered what was happening – and why I needed radiotherapy and chemotherapy. I was not fooled by the answers, which were initially blatant lies then some more ingenious falsehoods (including telling me I had TB).

It is extraordinary to think what was seen then as benign paternalism was in fact anything other than disempowering. The human mind is by nature an enquiring one, and we seek to avoid or to escape from difficult situations. As a result, being denied information feels like having a lifeline cut off.

While military metaphors have their limitations, they feel apt here. The illness was my enemy but my carers were not helping me. Once the initial treatment was over, they became bystanders as I lay in bed for months – and I still had no idea why. I tried to lift my spirits out of the black hole of despair by asking for information that could provide some hope, but my carers put all their effort into telling me to be quiet and that it was wrong to question them. Explaining this to an artist friend later, she produced the illustration on the next page.

The idea that patients will do as they are told was self-deception by a paternalistic profession. Like many other people I pieced together what was wrong with me and managed to view my notes when they were left outside the consulting room in outpatients.

Although I knew no one else who had been through a similar experience at that time, there are now similar published accounts.[2]

As a patient, being told lies made me feel insulted and diminished. The natural responses to those emotions are anger and pity that our carers could not see how much we needed answers to our questions; the breakdown in trust made me feel completely isolated.

Isolation is not merely a state of mind; it can be used as a punishment. As a sick youngster, it is hard to make sense of this, so I began to doubt my own powers of reason. Fortunately I knew from my ability to pass exams that my mind was working well, but I still felt injured. I racked my brain for an explanation – there was a hippy slogan at the time: 'Do not adjust your mind, reality is at fault' which provided some comfort.

Becoming a doctor

Having returned to good health and impressed by the curative power of the treatment I had received, I set off to medical school. To prepare us for the wards, we were instructed to be sober and courteous and avoid doing anything that might harm or upset the patients. This included not mentioning any words in the patient's hearing that could cause alarm. It instructed us to use euphemisms such as 'chronic disease' for tuberculosis, 'specific disease' for syphilis and 'mitotic lesion' for cancer.

There were endless euphemisms to avoid using the word 'cancer'. Surgeons would often refer to having removed a cyst, and physicians could be both inventive and evasive in referring to a touch of chest 'trouble' or a 'softening of the bones' for bronchogenic carcinoma and myeloma respectively. I argued for a more open approach and was told: 'Your job is to protect patients – just think what would happen if they knew they had cancer.' On another occasion, I was advised: 'You'll change your tune when you're older'.

I explained that most patients would be grateful to know about their condition and would appreciate being entrusted with such

An illustration depicting the authors childhood experiences feeling unsupported by medical staff in the face of illness.

important knowledge. If nothing else, having the information would help them to prepare for the treatment to come. One consultant demonstrated how he broke bad news to a relative, but not to the patient, saying the patient would not be able to handle it. I observed that patients often pieced together various clues (as I had done) and then expected to suffer in silence.

On becoming a registrar, I chose haematology as the best blend of science and humanity. It was clear that haematologists were quick to realise the importance of having well-informed patients. In the mid-60s the first trials of treatment for leukaemia used the term 'blood disease' when consenting patients for the trials. This soon changed, as the consenting process gave patients the opportunity to ask the natural questions, paving the way for a more enlightened approach.

One important feature of treating patients with acute leukaemias is the prolonged, almost intimate contact between patient and doctor. Usually a patient would be referred after suspicious blood test, I (as the doctor) would carry out the bone marrow, and a few minutes later I would be explaining the illness and what happens next. Often that would mean immediate admission, followed by weeks of intensive treatment, with home breaks between courses.

Over that period of time, a doctor gets to know their patients very well and they often would share their hopes, dreams and fears. As a doctor, I then had to decide the best way to respond; whether to hide behind the mask of professionalism and distance myself, or to try and be helpful. The mask often slipped, and patients usually started calling me by my first name early in their treatment (without encouragement). Over time I learned that simply acknowledging (ie validating) their distress could help. Questions often do not require detailed answers, but were instead seeking a response to indicate we as doctors had their best interest at heart.

In my later career

As a haematologist at a district general hospital, I have had the satisfaction of treating patients of all ages with a wide range of benign and malignant conditions. I have avoided specialising in those areas that could produce flashbacks and I happily referred teenage and young adult patients with malignancies to specialist centres. I have seen the issues that confront patients as they begin to cope with their illnesses and have taken a special interest in cancer support and self-care, speaking at many meetings and running workshops.

We now know that there is not one but many different ways of responding to the challenge of cancer[3] and there is a lot to be gained from enabling patients who choose to take a constructive approach.[4]

We need more study of how people adapt to challenging circumstances and what influences the adaptation. Early in the 1950s Balint observed that when patients offer their symptoms to doctors, they are not only giving a narrative of the illness, but exposing a great deal of themselves.[5] The doctor's response therefore delivers a judgement, albeit subliminally, of the patient themselves – if not in the content of the words, then in the manner of the delivery.

In the sensitive state of being ill and asking questions, such judgements can form a major part of one's self-image. Questions answered in a patronising manner make you feel that you are considered stupid and those answered in an aggressive manner makes you feel that you are being combative. Either way, you have a long journey of trial and error until you hit on the right approach or give up completely, probably leading to the long-term mental health issues well described in cancer survivors.

The traditional paternalistic approach may have been considered benign, but amounted to little more than kicking a man (or boy) when he was down.

What should happen?

A better approach than I experienced is now common practice in the specialist centres. Carers should be aware of patients' real need to their have questions answered and that it takes time for patients to assimilate or internalise what they are told about a life-changing situation. One conversation is not enough and communication can't be rushed – the journey through illness and treatment is more like a marathon than a sprint. A better analogy would be jumping a series of hurdles, a steeplechase or an obstacle course. Each new brings a new series of questions.

One survivor commented that she had developed a great sense of 'self' as she did not feel anyone else was on her wavelength. Normal people, my psychiatrist friend tells me, are unrealistic optimists. It can be depressing to dwell on the realities of what life has in store for you, so we keep our spirits up by looking on the bright side of life. We have a schema, a psychological term for dealing with issues, but with a force majeure like cancer our thoughts are temporarily derailed. We have to reconstruct and this is where a helpful hand could make a world of difference. Being made to feel powerless through illness strikes at the very heart of our identity and can encourage victimhood.

We regain confidence slowly testing every new situation tentatively, with help we can re-empower ourselves and feel whole again. It's worth remembering that the word 'healing' literally means to make whole.

In 1992 I went on a communication course for cancer doctors run at the Royal London Hospital. It was fascinating to hear colleagues' reflections on what they were learning about increasing openness, such as setting out on an uncharted sea, walking on thin ice and being subversive when they moved away from the traditional authoritarian doctor–patient relationship.

In retirement I run a support group (see boxout) and I continue to meet recently discharged patients. Many have been treated well, but this is not always the case. We need more doctors and more nurses, but we also need to learn from what patients have experienced to help us improve services. ■

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Patients supporting one another: the evolution of cancer self-help and support groups

When I first became a consultant in the 1980s, patients were still being patronised and misinformed. Although the Macmillan nurses had started to provide much needed help to some patients, many firms did not use them. Cancer support groups were becoming established, and the organisation I found most useful was the National Conference of Cancer Self Help Groups. Run by patients for patients, it was a glorious example of people coming together caring, sharing and learning together.

Many doctors worry that patient groups can be subversive or can be hijacked by other interests (eg commercial), but I was delighted to find that it was run according to the best practices of voluntary organisations with oversight from a charity called CancerLink, which later merged with Macmillan.

Through the group, I was able to learn more about coping strategies. Doctors like to be in control and know that traumatic events can lead to post-traumatic stress disorders. However, we must also recognise post-traumatic growth, which can be summarised in this quote from Eleanor Roosevelt: 'You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. I have lived through this horror. I can take the next thing that comes along'. Or perhaps more concisely by Friedrich Nietzsche: 'What does not kill me makes me stronger.'

The key point for doctors and their teams is to develop communication strategies that encourage post-traumatic growth and I have found that patient groups do that best.

I used workshops to ask what patients wanted in terms of communication with their doctors. A clear and unanimous response was 'answers to our questions'. I made a point of incorporating that in my daily work and also running communication sessions for the house doctors at my hospital.

From the mid-70s onwards, research has explained that not all patients are the same and introduced the Mental Adjustment to Cancer, subsequently the Mini MAC, to analyse patients' psychological responses to cancer. The cancer group experience has helped to add extra dimensions to this, including self-image. The press likes to classify patients as sorrowful victims or victorious fighters so most of us have had to think to ourselves that we simply do not fit. Coupled with the fact that few people are comfortable talking with someone about the emotional turmoil of their cancer experience can lead many patients to feel isolated.

The self-help and support groups can make a big difference to the individual simply by accepting them, knowing that the rollercoaster ride leaves most people dazed and confused and that merely acknowledging that their fear and confusion is the response of the normal mind to a threatening situation can relieve much distress.

The issues patients confront are often similar to other major changes and when I was sent on the King's Fund leadership course I found fellow consultants preparing to be clinical or medical directors expressing the same concerns as cancer patients in respect of their ability to cope. This underlines the need to acknowledge that fear and distress is a normal response – of a normal mind – best helped by support, not stigma nor avoidance.

There are a myriad of possible groups and organisational structures. Good practice guidelines are established[1] so that professionals can be assured that their patients are in safe hands. As a general rule these groups benefit from having one or two people with a professional background in caring but provided good practice is followed, this is not essential.

It has been remarkable to see how often people who have had bad experiences take the altruistic approach to help others to benefit from what has been learned. Sharing experiences gives group members the ability to know what is personal to them, and what is a general experience. One particular point is that although communication is improving, many doctors are clearly uncomfortable with difficult conversations.[2] It is a remarkable doctor who can meet all a patient's need by themselves, but a supportive network can. The groupwork guidelines are similar to simple good manners and most people instinctively know them. Having been a part of the Department of Health/ Macmillan Survivorship Initiative in 2008, which addressed the enduring issues of cancer patients once treated, I set about establishing a local group. Having retired from the hospital I had no authority and no resources but was able to establish a group with help from a local Rotary club and professional oversight from a hospice.

This has worked well, and we have a monthly meeting of people affected by cancer with occasional informal talks from professionals with people providing social support to each other. New people come and mix and mingle as they wish or enjoy the company without saying anything. What is different from the national meetings is how quickly conversation moves from the cancer experience to more enjoyable topics. Having reached an understanding that it is acceptable to discuss serious matters in a serious way people seem relieved and enjoy being able to speak freely. They have found a haven. ■

References

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