Learning from Patients

Many medical educationists are encouraging under- and post-graduate students to cultivate the habit of learning from their patients. This is seen as one's main, life-long learning strategy for initial and continued education. We invite you to send us an account of your learning experiences with and from patients. If not in the form of an article, why not write us a letter?
Editor.

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"A bad ball - game"

Roy Jobson

Summary

This case report deals with a patient with a seminoma: how he was treated by the medical profession, his ability to "see through" some of the games we play, and his interpretation of the cause of his tumour. It also comments on "honesty" in the doctor-patient relationship.

KEYWORDS: Dysgerminoma; Patients; Guilt; Patient Education; Communication Barriers; Personnel, Hospital; Physician-Patient Relations; Patient Acceptance of Health Care; Patient Dropouts; Attitude to Health.

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Curiculum Vitae
Roy Jobson, grandson of the late Dr and Mrs RD Aitken, matriculated from Kingswood College, Grahamstown in 1973. After internship (Baragwanath hosp) and National Service he spent a year in the United Kingdom, doing locums in general practices, during which time he became interested in Family Medicine. In 1985 he started the M Prax-med course at Medunsa. Roy trained as a telephone counsellor for Life Line while a student and has completed a Marriage Guidance and Counselling course at Unisa. He is married to Dr Marge Dawson and they have two children.

I was privileged to be able to share this patient's experience of his illness and to learn from him how easy it is for some patients to "know" intuitively how well integrated and whole the doctor treating him/her is. I also learnt from him the importance that many patients attach to finding a "meaning" to the illness.

A bad ball-game

The patient is a 45 year old clergyman who is married with three children. In 1979 he noticed a slight swelling of the right testis. He and his friends attributed this to being a side-effect of the Darachlor he was taking at the time. However after stopping the drug the swelling did not go away, but it gradually increased in size and became extremely sensitive to the touch.

He went to his his general practitioner who diagnosed it as a hydrocoele and suggested excision. The hydrocoele was removed and the general practitioner came to see him a few days later "with a face white with shock" to tell him that the swelling was cancerous.

A patient needs a doctor who will take overall and continued responsibility for his care.

That night he was admitted to hospital. The surgeon who would be doing the operation came to see him and told him that he would be "honest and straight" with him. He said that there was no way of knowing before the operation whether the tumour was of the more aggressive type or not, and warned him that if it were, they would be opening him from his neck to his pubis!

The rest of the night was very traumatic for him. He had found the doctors to be so clinical in their dealings with him that they were remote and showed no empathy. He felt that he was being treated so much as a clinical object that one had lost sight of the real person.

The next day he was operated on. Only the testis (and tumour), the spermatic cord at the internal ring, and scrotum were removed. The histology showed a 9,5 x 6 x 7,5cm tumour — a pure seminoma with no infiltration of the cord. He was told it was not the aggressive type of tumour, but that he would nevertheless need to have radiotherapy.

Ten days after the operation Cobalt therapy was initiated. No-one had warned him about the side-effects of DXT and he was unprepared for the mild radiation sickness (mainly diarrhoea) which he developed.

It is easy for some patients to know intuitively how well integrated and whole the doctor is.

He found that the worst part of the treatment was the sight of other people with their emaciated faces ravaged by cancer and the "stench of death" in the department. He was given a total of 5200 rad in 20 doses to the para-aortic area and the same to the right pelvis. There was a two week break after 10 treatments.

At the follow-up visit everything was found to be clear. There was no residual tumour locally and a chest X-ray was normal. He was told that he would not need any further treatment but that he would have to come back for regular review.

He then started to question deeply what had happened to him and to ask **"Why?"** Why had he contracted the disease and, being a clergyman, what had God wanted him to learn from it.

While internalizing his experience he began to realize that something had been "eating him up" inside, namely his attitude towards another person. He had been married to a woman ten years previously who had subsequently turned out conclusively to be a lesbian. She had been a very sexually provocative woman, always encouraging him to make sexual advances but never allowing him to actually consummate the marriage. It was eventually annulled on these grounds.

He thinks that — although he had at a conscious level forgiven this woman — at a gut level he had still harboured a great deal of resentment, and even hatred towards her. He is convinced that this is why the cancer developed in the very part where he was rejected *ie* his genitalia.

He was followed up three-monthly at first and thereafter annually for six years. He always disliked having rectal examinations done at these visits without it ever being explained to him what was being done or why. He has now been discharged from hospital follow-up and is regarded as cured.

Although grateful for the cure, he feels that it is just as much due to the visualization and self-affirmation techniques he was using, the homeopathic remedies he was taking, as to the surgery and radiotherapy. He turned to these complementary disciplines after he was discharged as he was given nothing to take and he felt a need to "take something to build his body up again."

If he were to get a recurrence or a different tumour he would not submit to further cobalt treatment or radiotherapy for two reasons:

i) He can't cope with the atmosphere in the hospital or with the medical staff who, he feels, are "the people most traumatized" in the whole process — hiding behind clinical apparatus and attitudes etc. He finds the concept of traumatized medics treating traumatized patients quite irrational.

ii) He couldn't afford it.

He would accept whatever treatment allopathic medicine could offer him in his own home and also go for as many different complementary medicine options as he could avail himself of. In his own words, he "won't put all his eggs in one basket!"

DISCUSSION

Darachlor is a combination of Chloroquin and Pyrimethamine used as an anti-malarial prophylaxis.

There is no mention in a standard pharmacology text-book[1] of testicular swelling being a side-effect of either of the ingredients individually or in combination. It is important to remember that a hydrocoele may be secondary to a tumour[2,3] and that histology of the excised portion of the tunica vaginalis should always be done. The testis itself should also be carefully palpated for any tumour.[4] A thickened tunica vaginalis should arouse suspicion of the possibility of an underlying tumour.[5] The surgeon was right when he said that it was not possible to tell pre-operatively what type of testicular tumour was present. A needle biopsy of a suspected testicular tumour should never even be contemplated,[6] as this may lead to dissemination of the tumour. The seminoma is relatively less malignant than the highly malignant papillary carcinoma, or teratoma, with its poor prognosis.[7]

The question of the surgeon's statement about being "honest and straight" needs to be considered. Stott[8] writes "The single most important determinant of the outcome of any relationship is honesty. People may get away with barriers of cover-up and pretence for short periods of time but any continuing relationship can only be stable if honest ***communication*** occurs between both parties" (my emphasis). Of course it can be argued that the patient's relationship with the surgeon is only a short-term affair, (unlike that of the family physician) and that he can "afford" to cover up his own feelings and inability to cope with how the patient might react by making dogmatic "no-questions" statements which appear to be "honest" — this probably being why he is a surgeon and not a family physician! Looking at Stott's words above, the missing ingredient seems to be the communication aspect. The patient wasn't given a chance to ask or discuss anything and, judging from his comments about it, he wasn't fooled by the "honesty" either.

Many patients need to find a MEANING to their illness.

Browne and Freeling as paraphrased by Stott[9] point out that it is common for strong feelings to be around when patient meets doctor and so misunderstanding or misinterpretation of the doctor's words and attitudes is likely unless the doctor is able to ***share personal attitudes with clarity and honesty*** (my emphasis). This implies that a whole lot of the responsibility rests with the doctor and to be able to do this he needs to know and be in touch with his own feelings and personality.

The question must be asked about the rôle of the family physician in this case — he could have been the link between the "cold and remote" specialists and the patient; retained the responsibility of being supportive and not "abandoning" him to them; ensured that the patient understood clearly what was happening and what to expect *eg* the side-effects of radiotherapy. This brings into focus the question of who the patient "belongs" to — does he remain primarily the family physician's patient entrusted temporarily to another doctor for a specific purpose? As McWhinney[10] states it, the patient "needs a doctor who will say, 'whatever your problem is I will deal with it. If it is outside my area, I will seek specialist help, but I will continue to take overall responsibility for your care."

In discussing the meaning that the illness has for the patient, I quote Browne and Freeling's[11] view that "Harrassed by the responsibilities placed upon us by our assumptive belief in single cause and effect relationships, general practitioners all too often employ an interrogative technique of investigation, thus denying the opportunity for patients to reveal their own perception of cause and effect in their own condition. Yet this perception is what is most important to the patient however inapposite the link they may make may be in terms of scientific knowledge." Stott[12] reinforces this when he says that "Perhaps the most ill-understood determinant of help seeking is the interpretation (meanings) the public attach to their symptoms and illnesses. Few Western clinicians even elicit such information at routine clinical interview: so powerful is the scientific bio-medical concept of disease causation that any other interpretation of causation or meaning seems trivial, inappropriate or primitive. This attitude may be valid in organic terms but it provides nothing except a communication barrier if the patient holds beliefs or interpretations of health and illness which make traditional clinical recommendations look illogical or inappropriate. The attitude also traps medical thinking into a framework which is often intolerant of other approaches, a view which is neither scientific nor sensible because many of the most pressing health problems are concerned with choices and behaviour." These quotes should "justify" the complementary medicine to "supplement" his treatment. Fehrsen[13] summarizes it as follows "If we neglect the personal element . . . people will find it in fringe medicine or elsewhere. If we dehumanize patients they will use us as body mechanics only and often inappropriately."

However, it is beginning to appear from various researchers that there may even be some validity in this patient's theory about the causation of his disease. Capra[14] states that "The connection between cancer and emotions has been observed for hundreds of years, and today there is substantial evidence for the significance of specific emotional states". Simonton[15] believes that "because cancer patients often have unresolved resentments, and other emotional attachments to the past . . .helping our patients learn to release the past is often essential in helping them get well." It is interesting that this patient was able to identify his resentment and make a connection between his past experience and the tumour. Another theory is that "life situations in which serious loss is experienced, can cause physical illness", the most obvious and most usually recognised loss being bereavement.[16] Levenstein continues " . . . there appears to be a causal link between feelings of helplessness and hopelessness, and various forms of physical illness which cover virtually the whole spectrum of conditions encountered by general practitioners in their daily work . . . there is no doubt that our patients are experiencing feelings of loss

in less obvious but nevertheless important ways . . . " It could be postulated that this patient's loss was that of self-esteem at not being able to consummate his marriage and at having to have his marriage annulled (especially coming from a fairly strict denomination of the church).

It is difficult to say whether his theory about the site of the tumour is valid — although there are anecdotes about the extremely "rigid" personality developing severe arthritis etc. One author states fairly categorically that "Moreover, the very part of the body affected is no accident, but is in accordance with the law of cause and effect, and again will be a guide to help us."[17] If in this case the patient's illness was, as he believes a lesson for him and a guide in rectifying an unresolved area of his life, it seems to have served its purpose!

This patient's need to "take something to build him up" indicates not only a belief system that many doctors do not take into account but also possibly the desire for the "continuous, if symbolic access to the palliative and nurturing presence of his doctor."[18]

Finally, some questions remain unanswered: Are the observations of this patient about the medical profession consisting of "traumatized" people who are enslaved by their discipline, valid? Are doctors also the victims of the "medical machine"? Is there anyone who looks after the emotional needs of the doctor and is he ever taught, except by "dubious example", how to cope with them? Shouldn't this be part of both under- and post-graduate training?

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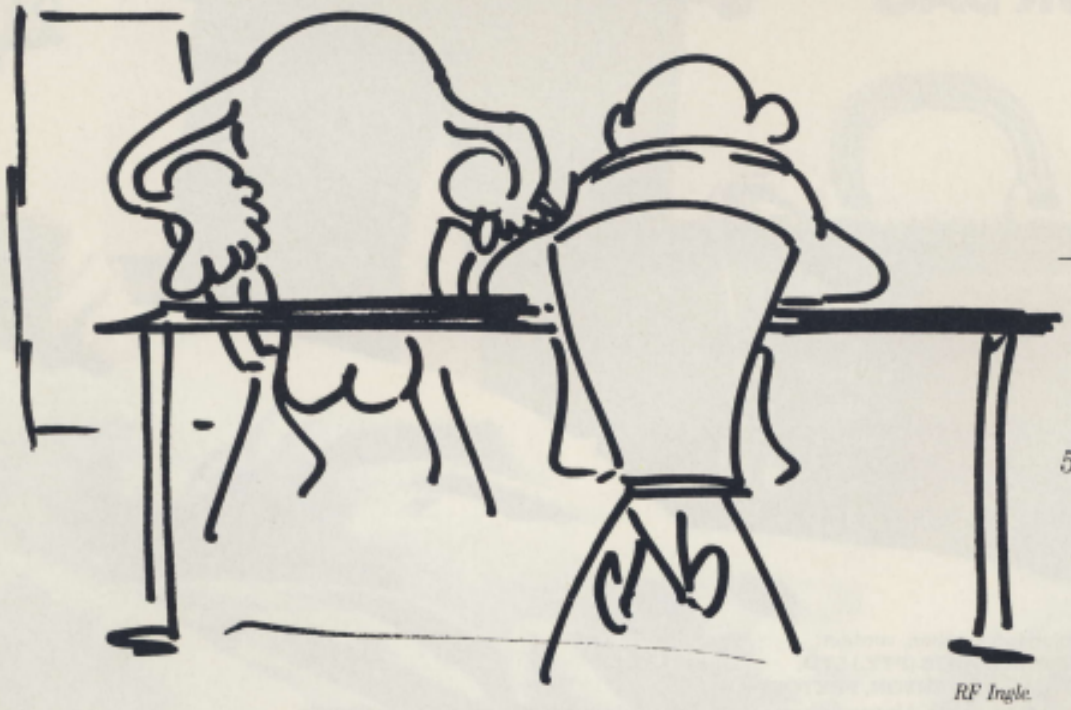
If you are also able to draw mind pictures as you meet patients, students or colleagues, please send them in for publication



RF Ingle.

— "Consider the patient as a whole and not as a pregnant uterus —" 5th year student