Views & reviews

Personal views

Age of innocence

Colin Douglas

In the 1950s there was great rivalry between the only two sizeable communities in northern Kirkcudbrightshire—perhaps there still is. The background, as usual in such cases, was complex. Our village had been cheated, by them of course, of a charter which would have made us a royal burgh some half a millennium previously. That still rankled. But we now had twice the population of the admittedly tiny royal burgh. And we had a secondary school and a far better football team.

But the rival village three and a half miles down the valley still had its attractions. Sometimes in the long summer holidays, when local diversions palled, a couple of us used to cycle across on a Wednesday afternoon to watch a regular event that never disappointed its 10 year old spectators.

In its main street the other village had a butcher's shop. Behind it was a well grazed paddock with a square stone building about the size of a double garage, bleakly and modestly equipped for its purpose. There was running water, electric light, and a selection of hooks and rails attached to the rafters. The floor was concrete, the walls whitewashed and splashed with blood.

On Wednesday afternoons when the shop was shut the butcher and his two assistants busied themselves in the building at the back. Small boys were not unwelcome, even small boys from the other village, though looking back on it I have a suspicion that girls might have been turned away.

We knew the butcher and his men because their van came round our village twice a week. Delivering steak, lamb chops, haggis, black pudding, and bacon to our mothers, they were cheerful, efficient, and amusing. On Wednesday afternoons, setting about another aspect of the business, they were no different.

As I recall it they did the beef first, hauling in from the paddock a steer, its eyes rolling and its legs splayed helplessly forward on the slippery floor. Then they tethered it and the senior man despatched it using a clumsy pistol that sent a bolt a couple of inches into its skull. The poor beast slumped, its troubles suddenly over, and was pulleyed up to hang head down from the rafters. Steel flashed and bright blood drained into an enamel bucket—next week's black pudding. Gutted and flayed before our admiring eyes, animal was made meat in less than half an hour.

Two or three sheep followed, light relief after the steer. And we could even help. Someone showed me how to connect one end of the detached intestines to the water tap and wash them out for sausage skins. See one, do one; then the satisfaction of a job well done, an adult mystery unravelled.

By the end of the afternoon the rails were hung with sides of meat, recognisably the kind of stuff that came round in the van. Hosing out the slaughterhouse was a jolly, jokey business with blood, urine, and faeces swirling together down the drain in watery absolution.

A ritual cleansing of our wellington boots and it was all over. We cycled home. However unimaginable—and for so many reasons—it seems today, that was what we did then. But there wasn't much else to do, and for small boys 40 years ago there were worse ways of passing a summer afternoon in the country.

Colin Douglas, *doctor and novelist, Edinburgh*

All treatment and trials must have informed consent

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In 1987 I was diagnosed with late stage cervical cancer—despite three negative smears that year and numerous visits to the doctor. I was told that I was having radiotherapy. I asked many questions, and my consultant explained the treatment as though it was a tried and trusted method, established for years. Eventually I was given the "all clear" and resumed my career. Six months later I returned to the hospital with severe faecal incontinence. I was advised that I might have radiotherapy damage and that I was "unlucky." I was then referred to a bowel specialist. He gave me unstinting support and inexhaustible, honest explanations. I never saw my radiotherapist again.

I was shocked to realise that I had not been informed of any risks before I consented to what turned out to be experimental treatment, only tested on mouse tails. I was admitted for a temporary colostomy and to have my rectum rebuilt. I met other women with radiotherapy injuries on the ward, and we had all been led to believe that we were unique. I was admitted over 100 times and had 24 operations, for adhesion attacks, a hernia operation, a permanent colostomy and urostomy, an operation to remove compacted faeces, formation then removal of both a rebuilt rectum and a mucus fistula, thrombosis, and so on. At present I have a vaginal fistula which intermittently allows faeces to escape through my vagina.

The repeated line of defence to patients who ask for explanations is: "Your injuries are a one off." A group of damaged patients joined together for mutual support and to prove otherwise. We called ourselves RAGE (Radiotherapy Action Group Exposure). A similar group of patients with breast cancer started in the south of England, so those of us in the north were called RAGE National.

We discovered that we had been guinea pigs in a clinical trial of a new radiotherapy protocol. We felt totally betrayed. We trusted the doctors, yet none of us had given our written consent even to treatment (only to the anaesthetic), and we were not given details about possible complications. An investigative journalist found out that we had been involved in trials without our knowledge. We could hardly believe him: this was Britain in the 1980s, not Hitler's Germany.

The more we discovered, the worse it became. Hundreds of women had been involved in clinical trials of radiotherapy to the pelvic area, and the morbidity rate rose to 57% in 1982. This was five years before I was treated: had nothing been learnt from earlier trials? Worse still, there was an almost complication free alternative, still being used, but no one gave us a choice.

Most women had no idea that their treatment was so toxic when they consented; not one of the women I have spoken to was told she was in a clinical trial; many have attended the hospital since for corrective or even life saving surgery. When a friend with early stage cervical cancer died from her treatment, not the cancer (which could have been cured by hysterectomy), we decided to go public and allow our names and photos to be published. Women are angry that others are still not being informed.

Women have tried to commit suicide as their lives have been ruined. Few have been offered counselling, marriages have broken, careers ended, children fostered. Many women cannot have intercourse. Some have developed social phobias, some are housebound through agonising pain and incontinence. RAGE has members from each year of the trials, all receiving different treatment schedules.

A RAGE member wrote: “Somewhere, somehow, I have to expose this abuse of power. The doctors never got my informed consent. This is abuse of society’s most vulnerable people. Where is there a platform for my voice to be heard, to make the public aware and the establishment accountable?” Some women only wanted an apology, or more understanding, or psychological support. More than compensation, patients want to protect future generations by ensuring that they are fully informed and do not suffer. Some consultants have shown humanity, by sharing information and giving examples of better practice: despite NHS pressures they have not lost sight of compassion.

Attitudes are slowly changing. Patients now expect to be told the details of the treatment proposed, together with side effects and complications. It is the doctor’s duty to state the facts, whether or not they are painful. Reading the Helsinki Declaration, I was troubled to think that clinicians today may even believe that sometimes there is no need for informed consent. We are living proof that nothing should be assumed. Protocols for the trials we were involved in were not even submitted to the local research ethics committee.

“It is our bodies that you are experimenting with.”

Our experience with RAGE tells us that patients are still not involved in their treatment decisions. Clinicians should understand that with new technology, patients can actively access information. If doctors do not provide this information some patients will obtain it anyway. Patients phone us saying that they have read the cancer charity leaflets and spoken to their consultants; now they want “the truth.” Patients want to talk to real patients, not those who purport to represent them, and current literature is not specific enough on toxicity. We have found that with careful questioning one can usually provide the level of information each individual wants to receive.

Many people are too shocked at the time of diagnosis to take in details about any treatment proposed. Consent to treatment or research should be sought later, at a second multidisciplinary consultation where the patient is accompanied by a relative or friend. Participants in trials should have easy access to the results of those trials, as a condition of partnership. Joint ownership of the work being done keeps patients involved, instead of isolating them. Psychological morbidity is as significant as physical morbidity; this too goes unrecognised and untreated.

There must be clinicians who genuinely want to learn about the patient’s perspective, who are brave enough to accept constructive criticism. When scientists have academic arguments about clinical research they should remember that they are dealing with people’s lives. We have feelings and opinions. We don’t want to be just another statistic: we’re real, we exist, and it is our bodies that you are experimenting with.

RAGE National, 24 Lockett Gardens, Trinity, Salford, Manchester M3 6BJ (tel: 0161 839 2927).

Ethnic issues in breast cancer treatment

I became aware that there was a problem when someone commented that Asian women are referred late for treatment of a breast lump. Anecdotal evidence suggests that some GPs still believe that Asian women do not develop breast cancer or that it cannot occur in young women. They, therefore, tend to dismiss the symptoms. The word “cancer” spells doom and death to many families and together with “breast” is taboo in Asian communities. As a result many women and sometimes their families become isolated.

When they do reach hospital the lack of empathy and ignorance about minority cultures leads to further isolation. When there is a language problem, made worse by the insufficient use of interpreters, there can be considerable distress. A survey in Leeds found that half the Bangladeshi population could not read or write English and 35% could not read or write Bengali.

After surgery many women are supplied with a temporary prosthesis and later a permanent one when the mastectomy wound has healed. But manufacturers have been slow to respond to the needs of women from ethnic minorities, possibly because of the lack of appropriately negotiated hospital contracts. Although temporary prostheses and several types of silicone prostheses are now available in varying shades of brown, nurses who work with women with breast cancer need to be better informed and sensitive to such issues so that the women are aware of the choices available.

A Leicester study on the management of breast disease in Asian women to assess factors contributing to anxiety, showed disturbing deficiencies in the counselling services provided. Many anxieties were not addressed because of the lack of professional intervention. Few women were counselled on such issues as the effect of surgery on personal relationships. Many women did not have access to a specialist nurse. The majority were not introduced to other patients with a similar condition; they would have liked that opportunity. The majority of women felt that their partners would have benefited from counselling. Few women were given information on Breast Cancer Care which has a free helpline for patients and carers. Over half the patients would have preferred information in their own language. When services, such as mammography, are specially targeted to local ethnic minority groups the uptake has greatly improved.

“Manufacturers have been slow to respond to the needs of women from ethnic minorities.”

Asian women in the Indian subcontinent have breast cancer rates two to three times lower than the observed rate in the British population. At present, Asian women who qualify for breast screening are mainly first generation immigrants and would therefore be expected to have the incidence of the country of origin. This is supported by evidence from studies in Britain. It is likely that the incidence in minority groups will rise as a result of increasing exposure to risk factors especially in second and future generations adapting to Western lifestyles. Certainly in the United States the risk for breast cancer in Asian immigrants has doubled over a decade.

Britain has the highest mortality from breast cancer; a contributing factor could be that women from minority ethnic groups do not access services at an early stage of their condition. There is a need, therefore, for strategically targeted educational material. Asian women need to be aware that they are also at risk of breast cancer. As 90% of breast lumps are found by women themselves, properly taught breast self examination could lead to a 20-30% reduction in the number of women presenting with positive lymph nodes.

The delivery of health services needs to be accessible, effective, sensitive, and appropriate to all groups of patients. This will mean changes to medical and nursing training as well as to health education.

Kulsum Winship, *chairperson, Breast Cancer Advisory Committee, Barnet Health Authority*