
Point of view

Ethics of cancer management from the patient's perspective

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Author's abstract

The face of cancer treatment is changing and the patient is both living longer and is increasingly able to articulate the problems of painful illness and look for solutions to problems which cannot be solved by technological advances. The cancer patient, like others, is looking towards the self-help movement to help him achieve a better quality of life. The doctor-patient relationship can be improved for both by a franker look at the present situation, the needs of the patient, the family, and those without family, especially in relation to cancer and its cultural connotations.

Self-help groups provide the support so often lacking in cancer management (including continuity), and a peer group within which adjustment needed to bring about the change in lifestyle required is achieved. Death need not be a word which is taboo, nor cancer a word which means Death. This is useful for doctor and patient alike.

I represent two aspects of cancer care – the patient (though I haven't had treatment for cancer for 14 years) and, as founder and chairman of PLUS for cancer and others in pain the new movement of self-help. I still feel angry about aspects of the management of my own case. Now, out of the experiences of the last nine years with cancer self-help, I have realised how individual management has to be. There is a need for the intuitive approach, a necessity for perception and fresh deduction for every individual – a need for moral standards and the dedication of the professional. The patient looks for achievement in the art of medicine; these are the ethics of medicine; with cancer, all these elements are highlighted. The ethics of cancer management are the ethics of medicine writ large. And how difficult they are!

So, I still have a lot of aggro about cancer, and the treatment of the cancer patient – which is different from the cancer patient's treatment. And I realise that the energy which has gone into PLUS has partly been a channelling of that aggro – into an attempt to supply that which I and my co-founders found lacking in the

health service, private medicine, social work services and the family. The close ones, the dear ones, have their own problems to face, and are often not as helpful as they would like, or want to be – at a time when the patient needs them most. And of course many nowadays, particularly the elderly, don't have family at all. Having cancer, suffering cancer, is a searing experience, and one is never the same again. The cultural connotations both for the patient and the professional are strongly negative. Accepting the stigma of isolation, the confrontation with mortality, is very important; it brings a fresh approach to life – which becomes good, has meaning, and it sharpens perceptions and allows fellow-feeling. But it took five years after my recovery to bring me to the point at which I could use my experience in the self-help field of cancer.

PLUS is for positive and also an acronym of 'Positive Learning Under Stress of pain'. It began in my house in 1980 and before many months consultants were referring patients to the house – members had done well beyond expectation. We took in those with pain from other causes to reduce the stigma. Now we have an Edinburgh office, a drop-in centre, seven paid staff, three branches in Lothian, two more forming, contacts all over Scotland and more than 250 families are presently members. The latest development is the formation of PLUS (National) and the beginnings of a branch in Fife. We are funded by the Social Work Department, Health Board, the Social Work Service Group, trusts and local businesses, and we raise some money ourselves.

Help has come from many sources; people who recognise the need for a certain kind of support which is so often lacking in cancer management – loving concern for the person, continuity of care, the right environment for recovery, and above all trust in the honesty of the professional relationship. In this atmosphere many who came as terminal did not die as expected. Many of the referrals are ones professionals find difficult and time-consuming. Many come tense and anxious about their reception, having before cancer diagnosis been classed as neurotic/hypochondriacs. J is one such. She has liver cancer now found to have spread to the pancreas. She once spent six hours waiting in a hospital for a consultant

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who was there, to ask about treatment and was not seen. She has been told both that it is not malignant, and that it is and no surgery is possible. I asked her what she would like me to say to you. I quote: 'Ask them to get their act together – say there's not enough follow-up. I have a month to wait now. Please take us seriously. I'm not bitter – there's no point in it is there? I'm going to fight all I can'. She will fight, she has a young daughter.

In cancer care surely there is a common purpose: the cure as far as it is possible, help for the dying if it is not, and support for increasing numbers of those chronically ill because of the efficacy of present treatment. But also there should be consideration of the patient as a person, an interest in how the needs of the person may be filled, so life may be lived to the full, whatever the span. The problems concern treatment and choice, the time to cease treatment, finding the right place for dying for the individual, or for recovery (not much cancer rehabilitation as yet) and how best to support the bereaved, because, it seems, dying is easier if that is secured. In PLUS we find many patients have come through largely by managing their own affairs. There is the Stage IV Hodgkins who refused treatment, who five years later has two daughters, a manual job and supports other Hodgkins sufferers. It has been very difficult for him, requiring strict discipline of his dietary regime and intensive spiritual involvement of a personal kind. There is the divorced bone cancer amputee who manages for himself with defiant independence. There is the loner-ex-alcoholic who found himself a room, used the group while having chemotherapy, then returned to his AA connections. Women can often find the discipline of a chosen diet an aid to recovery and feel it a security against metastasis.

The problem, for the patient, with medical ethics is that the patient's greatest good often conflicts with the greatest good for society, especially with regard to economics; and with the greatest good for medical and ancillary professions, in fields of personal involvement, time and research patterns. And once the greatest good of the patient has been identified in relation to the illness and treatment, plus the personal aims and goals in life – there is still the problem of the greatest good for the family. Add to that the distress of professional carers, and the requirements of research, and the extent of the conflict with the individual patient's interests is clear.

Even if we leave out society and what is economically possible, yet we cannot do that, these distresses are inextricably mixed. Having been both patient and carer and with my years of group experience I must say – with honesty – painful though it is to be carer, or responsible in these circumstances, it is very much worse to be the patient. Therefore it is to the patient we have to look for guidance about treatment, about palliative care, about the place to die and about how death is to come about. Cancer patients have a right to be consulted about how such money as is available should be spent in all these areas. In particular the

patient requires choice about what information he is given about diagnosis and about treatment, if there is a choice of treatment; and he has the right to die, ie, not be kept alive unduly by technological advances, and the right not to die while still wanting to live. Consent in trials must be informed consent. To be a patient necessarily means surrendering some control (but need it be all?), accepting loss of freedom, perhaps of life, and is, under our present systems, a frustrating and degrading experience. 'I do not want to enter the surgery and leave my personhood and capacities outside the door. How can I then use my resources to aid my recovery?', J said.

Not only does the cancer patient need to change in order to adjust to the system of lost identity and changed prospects – change in the medical profession towards less defensiveness, more honesty, more openness and to recognition of the patient's rights as a person is also needed. We need less of professionalism in the sense of outmoded paternalism and more of the kind of changes which would lead to easier management of the disease both chronic and terminal. Advances have lengthened prognosis for some disease – for instance the breast cancer patient who goes on to survive with three or four consecutive metastases – and thus have affected the length and degree of relationship with the doctor, especially the general practitioner.

MN felt abandoned by her GP but after her second metastasis, she courageously tackled him. He equally courageously admitted his discomfort and responded with support. MN raised several hundred pounds during her last fortnight towards the comfort of other patients on the cancer ward, in the form of the purchase of duvets. She was also our treasurer until the last six weeks of her illness.

To be a cancer patient means that you live in the present with the knowledge that you may be a cancer patient again in the future. Every cancer patient who survives treatment has to find the courage to live with that; and a special kind of empathy is needed. To face their situation may be the first step towards recovery – it restores stability. To say as is presently said by doctors, once a cancer patient always a cancer patient is less than helpful. Let us have cures – even if they are only temporary. Hope is a necessity, however hopeless it looks to the onlooker. At least let us enjoy the interim while being optimistic about the future.

The cancer patient is likely to be very frustrated and this frustration takes different forms. The frustration may be repressed and help needed; or it may be uncontrolled and vented with aggressiveness, some acting out or gamesmanship, and the game sometimes has to be played for a while at least. The most usual form seen in PLUS is the displacement of anger onto GP, physician, surgeon, radiotherapist, family or close friends and the making of a scapegoat. The turning inwards of the frustrations makes for the turning of the face to the wall, the reduction to hopelessness and helplessness which hasten the approach of death. The accompanying loss of contact with the carers brings with it a feeling of failure for all. By contrast an

awareness of anger and frustration, utilised in a creative way, intensifies the fight for recovery, changes attitudes to treatment, makes new relationships possible and generally increases the quality of life. Awareness leads to acceptance. It is this acceptance of one's personal mortality – 'death may be for me now before I am ready' – which makes it possible to go on living fruitfully.

Self-help and continuity of care

The sick one reduced to a passive needy recipient of care cannot be a person. Recently one of our members asked the consultant after treatment options had been discussed: 'Is there anything I can do to help myself?' and was told 'No, there is nothing'. The patient has an ability as well as a desire to participate. It was the resultant despair which brought her to us. Another, a man with Stage IV Hodgkins, in pain and well aware of his situation came in distress with uncashed prescriptions for analgesics he could not afford. He had four consultants in two hospitals who gave conflicting advice. He saw different members of his group practice. He wanted to return to work to finish his craftsman's job. It was a simple matter to solve the prescriptions problem – a call to the social work department at one hospital, but it was more difficult to get him back to work, yet his goal was a legitimate one, and would have solved the first problem. He handled his case badly, but in pain it is difficult to do it well; advocacy is sometimes needed. If a patient's family is perceptive and supportive, what they have to say is very relevant.

Checkups are very important to the patient. Lack of continuity can be very distressing. Many drop in for support before a checkup is due. Some return unsatisfied with five minutes' interview with a stranger. It is more than disappointment – there is deep unsatisfied concern which must affect the outcome. Cancer patients need continuity of care to avoid a sense of isolation and shame – the on-going support of a friend is vital. It is absolutely necessary to have at least one person to turn to, who knows, understands, is available between treatment and checkups, who can face the pain and is not dismayed as death approaches: in PLUS we like to work in pairs.

Honesty is not easily come by; especially about side-effects. The doctor appears to feel the patient should be grateful for continued existence and it is not always so – but the patient left with chronic pain from bone necrosis and unhealed rib fractures from radiotherapy finds it difficult to get an admission as to the cause of pain, or the extent of the disability. And this lack of honesty exacerbates the problems, producing anxiety in a frankly anxious-making situation involving an uncertain future. A downright denial of chest pain in G, which proved to be pericarditis, is an unfortunate example of what I mean. The patient also finds it difficult to be honest about feelings and prospects and sometimes projects the anxiety about the cancer onto other illness or disability and finds comfort in it.

Communication Honesty in communication on the other hand can be downright brutal. Here the question to be asked is: 'How sure can you be of your poor prognosis?' Four years ago L was told: 'You've come too late, go home and make a will – make it this week. You'll be lucky if you have three months'. She had her treatment and is still with us. Not enjoying life very much. Still waiting to die. Perhaps even if the information had been conveyed more gently she would still be depressed, but the point is – in the light of present treatment was the statement justified?

Information How much and when are issues over which the patient usually has little control. But only the patient is aware of how much information he wants to know if life is to go on at a productive level. If he doesn't ask he usually doesn't want to know. Of course he may be afraid of being snubbed, or of his question being left unanswered leaving him open to worse fears; he may be afraid of medical distancing and defensiveness. If the doctor has not faced his own mortality and fears, conscious and unconscious, his professional inability to cure in the definitive sense, his feeling about the possible loss of the patient and the repercussions in the family, then both he and the patient are going to have a difficult time. And the patient becomes very well aware of the doctor's dilemma.

As patients we want to be able to trust our doctors. Most of us do not want legislation for active euthanasia. We want informed clinical judgement about when to stop treatment. We want sufficient drugs to control pain if it is possible. We want to remain clear-headed to be able to attend to our affairs and relate to family and friends. We don't want to pretend pain is controlled if it is not – in order not to offend. We want to use our gifts and talents to the end. We want to be treated lovingly, knowing we may become unlovable. Most of us would like to die at home in our own surroundings, and hope we will still have friends there when we do.

To sum up: We need help with frustration, anger, isolation and to face death and chronicity. We want equal and free access to treatment, and support during it, and afterwards. The main ethical decision in cancer care concerns quality of life. If money is unavailable lateral solutions must be found. Even if we can't get more money, why not a new philosophy? PLUS offers one such.

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Milly Jolley qualified as a pharmacist from Manchester University. After developing cancer she became a professional artist. Limited by her husband's condition of heart failure in 1980 she began a house-group focusing on self-help in painful illness. After his death in 1982 she developed this and opened a drop-in centre which offers a variety of activities and a transport system.