

Annotated Bibliography for Medical StudentsPrepared for the Study Day with Final Year StudentsIntroduction

This I hope will be an "ideas pack" in which you might find articles to browse through at your leisure, when you think your mind might be open to ideas.

The first part contains comments about papers worth reading for the ideas they contain.

The second part is made up of important source articles which give a good foundation on which to build - listed on contents page 1.

The third part, the Appendices, contain one or two lists of questions about cancer, which patients might ask, and an advertisement of the Cancer Research Campaign which is a statement of positive messages about cancer. There are also sources of more information, some of the questions you might find useful when you chat with a cancer patient and the relative of one, and finally an example of a cancer patients' Bill of Rights.

The collection of disease called "Cancer" is feared by patients and doctors alike. These diseases are chronic - they are liable to flare-up or relapse again after primary treatment - so coping strategies have to be those which would be used when facing any chronic illness. Since major cancers can kill, patients have the additional stress of fear of death and fear of pain.

Some patients come to us when they are quite near to death. They need help to die with dignity and no pain. You will explore their management when you attend the Hospices. To find out more you need to explore the works of Dame Cicely Saunders, Dr Elizabeth Kubler-Ross and a book by Robert G Twycross and Sylvia A Lack, Therapeutics in Terminal Cancer.

The theme of this bibliography is to help make living better for the Cancer Patients. It is important to remember that after the diagnosis of cancer there may be a long period of life, the quality of which can be ruined if patients spend their time in worry and fear without sensible support from us and our staff.

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Chapters to read from Books

Professor D Goldberg of Withington Hospital, Manchester - see page 17 in this booklet has written:-

The Nature of Psychological Healing, Chapter 21 in Current Themes in Psychiatry, Vol 1, 1979, page 219
Ed: R N Gaird & Barbara L Hudson

This chapter is an entertaining account of what "healing" is. It shows how important the healer's own attitude is when trying to help the patient. It is written for psychiatrists but applies to all doctors. It dwells on that important thing, the placebo effect, which has been such a useful "drug" but which doctors of the 1990's tend to despise and disregard. The placebo effect is not plain trickery like giving sterile water for pain, (which I will always oppose and never do), but rather the encouragement of the patient to get better, by putting faith in the treatment which you are giving in good faith, because you believe it is for his good. It is possible to encourage healing by encouraging the patient to use belief systems in which she does have faith - physical things such as diet, (under your careful supervision) and spiritual forces such as her faith in the God she worships. It is no part of a doctor's job to destroy what a patient believes in unless that doctor is prepared to take time to replace it with something else. Professor Goldberg indicates how faith in healing has been used in various ways. His ideas might give some help when you are trying to encourage patients with chronic conditions, like cancer, or even rheumatism and diabetes.

Dr Peter Maguire (also of Withington Hospital) - see page 32

Doctor-patient skills, chapter 3 in Social Skills and Health

Ed: Michael Argyle, University Paperbacks, Methuen, page 55/81 Year 1981

This book is one for your bookshelf. It does not matter what speciality you end up in, a doctor deals with people and is expected to do it well. All of this book is worth reading. Chapter 3 alerts us to the deficiencies we all have. If we are aware of them we can do something about them, so long as we are prepared to do so. Of all patients, the cancer patient needs help from a doctor open to exchange of ideas and sensitive to the fear he has: a) of the doctor and the powerful effect he or she will exert and B) of the disease, the outcome of which will remain uncertain till death approaches. If we develop our doctor-patient skills to help the cancer patient, then all our other patients will get a better deal from us.

Peter Magurie has written a lot about Communication and how important good quality information (together with a warm thoughtful attitude in the doctor and nurse) is in helping a patient in a "bad place". Intervention reduces depression and suffering.

Dr Lesley Followfield who works with Professor Michael Baum in the Royal Marsden Hospital, London, has done a lot of work on patients' attitudes and the psychological trauma of surgery. She is an experienced psychologist who has prepared a bibliography for a course on breaking bad news. Please see page 46.

Science versus the Absurd

Quack Cancer Cures or Scientific Remedies? Clinical Oncology 1981 9 275-280

Notes the important contribution Prince Charles has made in the promotion of alternative therapies in the 1980's and sounds a word of caution about encouraging alternative therapies. In my view every thinking doctor who cares for the physical needs of his patient would take responsibility for the psychological health of the patient and would encourage spiritual growth if the patient wants it. This is true holistic medicine. If the patient turns away from us into alternative medicine he may come to harm.

Rationalism versus irrationalism in the care of the sick page 50

In this leading article in the Medical Journal of Australia, Professor Baum develops a clear argument about how a scientific doctor in the 1990's should view alternative medical therapy.

**Healthwatch, The Campaign Against Health Fraud, Box CAHF,
London W1N 3XX, Tel no 081 6736270**

The Campaign Against Health Fraud publishes a regular newsletter to promote good practices in the assessment and testing of treatments whether orthodox or alternative, as well as supporting consumer protection. At theme in is is that better understanding by the public and media of valid clinical trials is the best way of ensuring the public's protection. The subscription costs f12 a year and is well worth it for the insight it gives.

Quality of Live

There are numerous methods which have been proposed to measure the quality of life but this remains a difficult measurement to grapple with. Some studies of cancer treatment report measurements of quality of life. The best exposition of the complexity of this subject that I know is the paper by Ken Calman "Quality of Life in Cancer Patients - an hypothesis". See page 54.

Diet and the Cancer Patient

This is considered in "The Case for a Real Alternative in the Treatment of Cancer" page 52.

This interesting article has been extremely useful to me. Dr Pietroni's guidelines to a healthy diet are important for our good health so naturally a patient taking such a diet would have the best possible chance of being helped even in the face of quite a serious illness.

The point to make is that what scientific evidence we have on diet and cancer is about prevention of cancer by alternating the diets of nations. (Peto and Doll: The Causes of Cancer). The treatment of cancer by diet is wholly unscientific. However many of these diets also have guidelines similar to these of Dr Pietroni.

A very interesting book which will arm you with a lot of information about the nature of cranky diets is:

Fresh Hope in Cancer

M Finkel, Health Science Press, Bradford Holsworth, North Devon 1978

This book is important because it summarises the diets and repeatedly states that patients on these diets should never have a biopsy! This seems to be the core belief of the cranky diet brigade and explains how cancer is "cured" by these diets! (It probably did not exist in the first place).

If a patient wants to try a special diet, then get him to show you what the diet is to be. A healthy diet in the 1990's is described in Dr Petroni's paper on page (A discussion paper: Proposals for nutritional guidelines for health education in Britian: NACNE September 1983: Produced by Health Education Council, is the official source for diet guidelines).

The diet should contain enough calories, together with the Cal-protein-fat ratios recommended in Pietroni and NACNE. So long as these basic principles are respected you can go along with any sensible diet, but look out for those diets that are 'cleansing'.

This usually means starvation in an expensive disguise. It is also important to find out what the patient wants. Patients can be unmercifully pressurised by well-meaning, one eyed spouses, relatives or friends when all they want to do is eat a bit of what they really fancy.

Finally, if a patient decides to follow a special diet, which you can see is sensible and reasonable, it is good idea to persuade her to stick to the first diet that she chooses rather than go from one diet to another in the health food magazines which fill the shelves of some news vendors.

The Bristol Centre

Survival of patients with breast cancer attending Bristol Cancer Help Centre

F. S. BAGENAL D. F. EASTON E. HARRIS C. E. D. CHILVERS
T. J. McELWAIN

The Bristol Cancer Help Centre (BCHC) was set up in 1979 to offer various alternative therapies and treatments for patients with cancer. It attracted much public interest and a high demand for its services—and profound medical scepticism. In a study beginning in 1986 of 334 women with breast cancer attending the centre for the first time between June, 1986, and October, 1987, information about the diagnosis was obtained from case notes. Controls were a sample of 461 women with breast cancer attending a specialist cancer hospital or two district general hospitals. The same information was obtained for the control group as for the BCHC group. All patients have been followed up to June, 1988. 85% of patients with breast cancer attending the BCHC were aged under 55 at diagnosis. More than half had experienced recurrence of their disease before entry. For patients metastasis-free at entry, metastasis-free survival in the BCHC group was significantly poorer than in the controls (relapse rate ratio 2.85). Survival in relapsed cases was significantly inferior to that in the control group (hazard ratio 1.81). For cases metastasis-free at entry to the BCHC there was a significant difference in survival between cases and controls, confirming the difference in metastasis-free survival. There was no significant difference in survival or disease-free survival between the cancer hospital controls and other controls.

Lancet 1990; 336: 606-10

The Bristol Cancer Help Centre (BCHC) was set up in 1979 to offer alternative treatments for patients with cancer. The stringent "Bristol diet" of raw and partly cooked vegetables with proteins from soya and pulses attracted much public interest and a high demand for the services of the centre—and deep medical scepticism.² The ideology of the BCHC is that the cancer patient can contribute to the healing process in a positive, active way. The diet, though still a central part of the treatments on offer, has become more palatable and adherence to it is now tailored to the individual's needs and state of health rather than to his or her willpower. The centre also offers counselling, "healing", and alternative therapies claimed to enhance quality of life and help to develop a positive attitude to cancer. Patients may initially attend the BCHC for a week-long course or for a single day.

This study began in June, 1986. BCHC staff and patients felt a need to validate scientifically the results they felt had been achieved. They invited a team of doctors and scientists (T. J. McE., Lord McColl, Sir Walter Bodmer, C. E. D. C., and Dr Peter Maguire) to discuss how this could be done. Two studies were proposed, this one and one that evaluated quality of life. Both the staff and the patients at the centre and the patients' consultants have cooperated fully. The study is restricted to women with breast cancer attending the centre for the first time; one-third of all BCHC clients have a diagnosis of breast cancer.

Patients and methods

Cases

Since this article was published there has naturally been a lot of controversy. This can do nothing but good because alternative therapies are not being subjected to scientific scrutiny in Britain or anywhere else to my knowledge. The US Office of Technology Assessment has just published a 300 page report "Unconventional Cancer Treatments" in which none of the unconventional treatments, for instance macrobiotic diets, coffee enemas and immunoaugmentation therapy, were found to meet recognised scientific standards of proof of effectiveness. Main stream cancer treatment comes into criticism mainly it is thought, because of the failure of doctors to take account of issues relating to patients' quality of life. As far as I can tell the British Chiropractic Association promotes the only alternative medical treatment which has been subjected to scientific scrutiny. In the BMJ in June of 1991 the MRC published a study of 700 patients with back pain, treated conventionally and by chiropractors. It was concluded that the chiropractic treatment gave better results which lasted longer. All other alternative treatments remain to be tested.

Communication Skills

- R Sanson-Fisher & P Maguire Should skills in communicating
with patients be taught in
Medical Schools?
Lancet 523-626 (1980)
- A Tait et al Improving communication skills
Nursing Times 2181-2184
(1982)
December 22/29 (1982)

These two papers should be read with each other. The first is full of quotable quotes eg, "another reason for complacency of many doctors about their competence in communication skills is that their patients do not usually give them feed-back about their deficiencies". The second is full of useful hints and examples of exactly what words you can use when you are trying to improve your skills.

Mr Brian Hogbin a Surgeon in Brighton gives patients a tape of the "Giving of Bad News" interview after he has gone through it with them. (BJ Hosp Med 4 330-319 1989)

Counselling

Counselling cannot be taught by papers and books. It can be learnt slowly and best by attending a counselling course run by a teacher you respect and who is sufficiently skilled. One way to get an idea of what is involved in counselling is to listen to a series of tapes about it, eg:-

Principels of Counselling: Series 1 Units 1-8
 4 cassette tapes with notes and exercises
 £16 (p&p 80p)
 by Francesca Inskipp and Hazel Jones:
 Alexia Publications
 2 Market Street
 St Leonards on Sea
 East Sussex

The British Association of Counselling,
 37 Sheep Street
 Rugby
 Warwickshire
 CV21 3BX
 0788 57832879

is worth joining.

Its aims are:-

PROMOTE understanding and awareness of counselling throughout society.
INCREASE the availability of counselling by trained and supervised counsellors.
MAINTAIN and **RAISE** standards of counselling training and practice.
PROVIDE support for counsellors, particularly opportunities for their personal growth, education and training.
RESPOND to the increasing demand for information and advice concerning both counselling and counsellors.
REPRESENT counselling at national level.

Towards these ends, the Association brings together the commitment and resources of a wide range of people, through individual and organisational membership.

About Student's attitudes

H H Haley et al	Students attitudes towards Cancer Changes in Medical School J Med. Education 52: 500-507 (1977)
R E Cohen et al	Attitudes towards Cancer Cancer 50: 1218-1223 (1982)

These two papers use similar methods and go together (the 2nd leans quite a lot on the first)

NB As students progress through their training, they have increasingly negative attitudes towards the value of early diagnosis and aggressive treatment but increasing confidence in the patient's coping ability and ability to prepare for and accept death.

A Patients Right to know

There is a good deal of interest in the patients rights to information. The Medical and Dental Defence Union of Scotland to whom I applied for information states:

"Case sheets for NHS patients in England and Wales belong to the Secretary of State for Health. The legal right to these is vested in the Health Authorities. In the case of a private patients, the notes are the property of the practitioner. The information they contain is the property of the patient.

"I think you would find helpful information in the following:

GMC Professional Conduct and Discipline:
Fitness to Practise, paragraph 79 to 82

Patients' Rights published by
The National Consumer Council, Chapter 3
information

The Handbook or Medical Ethics,
BMA publications

Law and Medical Ethics Second Edition,
Butterworths Mason & McCall Smith, Chapter 9

"We commend all attempts at openness and improving communications between doctors and patients. So often poor communication resulting in resentment and anger is at the basis of claims".

ACCESS TO HEALTH RECORDS ACT 1990

This new act gives individuals the right of access subject to certain exemptions to help information about themselves recorded from the 1st November 1991. This means that if they choose they may read what you right about them. It is therefore essential to remember this when making notes from now onwards.

Various agencies have recently published "Bills or Rights". The one published by Cancerlink is as clear as any. (See appendix G). Information giving to the cancer patient has been discussed in the "Cancer Patient's Right to Know" by Mary Cassey-Jacob, Cancer Topics volume 5 no 9 November/December 1985 page 106.

I have used Brian Hogbin's idea, taping complicated or Bad News interviews on a Walkman and giving patients the tape to play over and over when they get home. From it I have had lots of positive feed-back. Although it is still not part of my routine practice I have found it useful especially because I can "dictate" a bit with the end of the tape to summarise what we said. It is that summary I write in the note.

Informed Consent. There has been a great deal of argument about this in the Surgical Press over the years. A good discussion is found in **Surgical Informed Consent** - what it is and is not, W Edwards and C Yahme, American Journal of Surgery volume 154, December 1987, page 574-578.

The NHS Management Executive has published "**A Guide to consent for Examination or Treatment**". Since this is an official document, easy to get and important I recommend that everyone reads it. The specimen consent forms are controversial but all hospitals were required to produce new forms for their use before the end of 1990.

Honesty

Doctors are often accused concealing the truth. In our social dealings with each other we often say dishonest things in our "lies of politeness". The argument for honesty and integrity in medical life has been best made by Richard Clarke-Cabot in his important book "Honesty" published in 1938. David Short (BMJ volume 296, 1169, 23 4 1988), in reviewing the book, is primarily concerned with the widespread tendency for doctors to deceive their patients. He observes that this is generally done not because it is better for the patient but to make life easier for the doctor. He goes on to point out what is often overlooked, that when a patient discovers that he has been deceived his mistrust is focused not soully on the doctor who deceived him but extends to the medical profession as a whole.

Cabot argues persuasively that honesty "should be automatic and without exception, apart from jokes, games and drama where there is implied consent to deceit". Many doctors would claim that, important though honesty is, kindness is even more important. Cabot rejects this contention. He argues that all human beings, doctors included, are strongly prone to self deceit and self justification. The argument that dishonesty is the best policy in a certain situation is merely the doctors convenient and fallible opinion. He also argues that lies, even well meant lies, have an adverse effect on the liar, "especially when he lies on principle".

Cabot makes a strong case for the cultivation of a habit of honesty. Although he admits that circumstances have to be taken into account he does not accept a stand-point of "situation ethics which rejects guidelines". He argues forcibly the need for "fixed rules".

He points out that often a decision whether to tell the truth or not has to be made suddenly and an emergency is not the time to make careful judgement where an exception to the general rule of honesty is required.

As Cabot puts it "in time of temptation no human being can be trusted to make the exceptions fairly", therefore "any valuable moral rule must be nearly or quite automatic".....

He emphasises the need to be honest with ourselves to say the truth at all costs; and to be honest in practice, in our financial dealings, family relationships and friendships.

Short recommends "Honest" as a book worth re-reading. He says Cabot does not advocate forcing the whole harsh truth on the patient unsought, and he distinguishes between "brutal frankness" and "truthful reserve". Brutal frankness is after all the way of opting out of gentle care for the patient. I would suggest gentle frankness with patients followed up by asking if you have provided enough information for their purposes. If they need and want more you can be more precise. Some people wish to know almost where every metastasis is situated while others want to know nothing after they are told the diagnosis is "cancer". Sensitivity to each individuals needs coupled with absolute honesty is a good plan because it breeds respect on both sides and means that lies do not need to be remembered. Hogbin - in the pursuit of openness - uses a tape (as I have described above).

What does a patient want to know?

R L Davidson **Questions about Cancer** J Inst. Health Ed
21: 5-16 (1983)
The commonest cancer questions asked by the
public in 6 different centres

This is a very good source article for anyone preparing to talk to the public about cancer and any aspect of it.

A Eardley **What do radiotherapy patients want to learn**
Radiography 49: 122-124 (1983)

Health Education by Chance: Ann Eardley et al Int J Health
Ed 18: 2-8 (1975)

The unmet needs of patients in hospital and after are laid out in these papers.

A book which is written in question and answer format and which is an excellent source for answers to patients questions is:

The Cancer Reference Book by P M Levitt, Paddington Press
N.Y (1979)

See also Appendix A - questions that people ask about cancer and radiotherapy

The Sick Role

This is a basic and important concept to recognise in any patient with a chronic illness. Dr Maguire refers to this in the paper referred to above by Sanson-Fisher and Maguire.

The Sick Role and its relevance to Doctors and Patients (Anne Eardley, Practitioner 219, page 385-390) is a paper in which the sick role is considered and described. Emphasis is given to the important part the patient plays in getting well again when the illness under consideration is a chronic one like cancer.

Coping

Coping with Physical Illness

Ed R H Moss Plenum Medical Book Co (1977)

An excellent source book for ideas and examples.

Coping with Cancer Stress

Ed Basil Stoll: Martinus Nijhoff: 1986

A collection of papers on the impact of cancer on the patient and support of the cancer patients together with a personal statement by a patient.

Hope

Whatever our feeling about the final outcome, it is important to maintain hope. A Widow writing a personal paper in the Lancet, 19th November 1983, made a very clear statement about this. She says "Professional Staff have no justification in destroying hope in patients or relatives particularly at the initial stages of diagnosis".

Norman St John-Stevas in his autobiographical book "The Two Cities" has a chapter on Hope, in which he quotes St Thomas Aquinas reflecting on the relationship between youth and hope: a "Youth is the cause of hope on these three counts, namely, because the object of hope is future, is difficult, and is possible. For the young live in the future and not in the past, they are not lost in memories but full of confidence. Secondly, their warmth of nature, high spirits and expansive hearts embolden them to reach out to difficult projects: therefore are they mettlesome, and of good hope. Thirdly, they have not been thwarted in their plans and their lack of experience encourages them to think that where there's a will there's a way....." (Summa Theologica 1A-2AE, KL6)

In the matter of hope let us all try to stay young in our hearts.

Time to let the Patient speak:-

is the title of an article by Dr J Blau BMJ volume 296, 7th January 1989 page 39, in which he describes an experiment on a hundred consecutive patients referred by letters from their family practitioner to NHS clinics in which he worked. "70% of patients spoke two minutes or less. The overall average was less than two minutes. This brevity with which patients describe the symptoms was suprising". He quotes C Clothier in the Patients Dilemma, published by the Nuffield Provincial Hospitals Trust 1988. "Listen to the complaints of the patient however tiresome or irrelevant that may seem. He will eventually tell you what is the matter with him..... It is usually better in time and care to let him come to a natural halt from exhaustion of either the speaker or material".

It often supprises me how quickly people tell me their history if I sit and listen after asking "what has brought you here" or "please tell me what is the matter with you".

A Difficult Patient

When we consider breaking bad news we often worry in case the patient himself will be difficult to deal with. Two articles in the BMJ for the 20-27th August 1988 make a wonderful short summary for the problems doctors meet when they have a difficult patient. They are "Five years of heart sink patients in general practice" by T C O'Dowd BMJ volume 297 page 528 and "Difficult patients, black holes and secrets" by T J Gerard, and J D Riddell, BMJ volume 297 page 530.

Having said it I must admit that I have met very few of these people amongst those to whom I have had to give bad news about cancer.

They are a small minority of our practice and if we can recognise them and work out strategies for their management, our lives can be more comfortable and our professional relationships much more healthy and genuine.

Self-awareness Movement

There are many aspects of self awareness which have been explored especially across America in the last few years. They are all reviewed in an excellent book called "Lets talk about Me" by A W Clare, BBC publications 1981.

A critique of the self-awareness movement appears in the British Association of Counselling Journal Issue No 52, page 19-24 May 1985 by Chris Scott. This article is particularly useful because it emphasises how self-centred a lot of this work is. However, if some of the techniques are applied sensitively, and with discretion, they can be very helpful to the cancer patient.

Positive Messages

Positive messages come from your own experience and the experience of patients and their relatives who have met cancer and survived. Sometimes positive messages are published in newspapers eg The Cancer Research Campaign advert (Appendix B) but on the whole nearly everything we read in newspapers about cancer is very negative and hopeless or else ridiculously overstated "Cancer Researchers claim another breakthrough", etc.

The Power of Positive Thinking

N V Peale A Cedar Book No 100 Worlds Work Ltd,
23rd Impression (1990) ISBN No 0-7493-0715-3

This book is full of ideas about how positive thoughts can be put to use in developong an encouraging attitude to life.

People with cancer are going to ask you for help in seeking out positive messages of hope and enthusiasm. You might find positive and enthusiastic thought in a book such as:-

Anatomy of an Illness

N Cousins, Bantam Books (1981) as perceived by a patient.

This book encourages patients and doctors to pay attention to the placebo effect amongst other things. It is quite an inspiring book and fun to read.

If your patients is a Christian or favours Christian beliefs he can find a lot of positive messages in the literature on healing, eg **Christian Healing in the Parish** Grove Booklet No 42, published by Grove Books, Bramcote, Notts (1985). This booklet costs £1.05 including postage and if Grove Books have run out of them I might still have a copy for you in Airedale if you want it.

If you are interested in Alternative Strategies to help your patient you might like to read "**Getting Well Again**" by Carl Simonton, Stephanie, his wife and Dr Creighton (Bantam Books 1981 - £1.95). This team of Oncologist, Psychologist and Radiotherapist have worked out a patient self-support method they call "imaging" which forms the basis of the current do-it-yourself/gentle way "cures" of cancer used in places like the Bristol Centre where they also pay of lot of attention to an uncooked vegetables/vitamin diet which has been all the rage with patients striving to help in their own management of cancer in the recent past. Such a diet is discredited but will certainly come back into vogue again sooner or later.

Cancer and the Mind

Ed: M Slevin and Robert Short, proceedings of an International conference published by British Journal of Hospital Medicine: Conference supplement 1990, contains 17 articles on aspects of personality, emotion, psychology, relaxation etc as they relate to cancer together with a patient's view on what she wants from a Cancer Doctor. It is worth an evenings reading.

Support of the Cancer Patient

Ideally the doctor and nurse attending the patient would supply enough to satisfy the needs of a cancer patients, but this is not an ideal world and professional staff may not have enough time (or inclination) to help the patient face the problems of his chronic state, or the patient may want more than is reasonably easy to supply.

There are two effective ways of supplying more support:-

1. Train a professional to support staff dealing with cancer patients
 - a) develop the communication skills of a professional helper, eg district nurse/social worker/other, to provide support for the patient on a one to one basis.
 - b) since they themselves need more support this can be given by a trained supporting counsellor. (All counsellors of quality require a supervising counsellor).

Peter Maguire has pioneered this excellent method but its use is not widespread yet and you may have to support your supporter with psychiatrists, psychotherapists. The problem with using a professional is that once their case load is full they cannot cope with any more, and the need for support of patients is limitless.

2. Establish a Cancer Support Group

The other way is to form a Support Group. Such a group needs carefully trained leadership. If such leadership is available the support that patients can give each other is impressive and valuable. If the group is badly run (or set up by people without any training) it is quite likely to fail and damage the patient. Since leadership is important training is required for it from a trainer who will encourage and enable the members for the group to develop into people who can cope and know they can. An excellent model of leadership and training is provided by **Tak Tent**, the Cancer Support Group Organisation in Glasgow. See Appendix C.

The books to read if you want to take an interest in Support Groups for cancer (or any other chronic state) are:

Growth Groups - H Clinebell - Abington Press (1979)

About group dynamics and where groups can be effective in school/work/church etc. Packed with ideas and with extensive reference lists

Grow to Love - Jean Grigor - St Andrews Press, Edinburgh 1982

A resource book for groups, giving theory and practical ideas in a Church setting. An important book to read for anyone wanting to know a bit about Groups and how to lead them. Anything by Jean Grigor is worth reading.

Using Groups to Help People - D S Winter - Routledge and Degan Paul, 1985, ISBN No 0-7102-1095-7

A comprehensive guide to group work

Born to Win - M James, D Jongeward - Signet Books 1978

This book is an introduction to Transactional Analysis with Gestalt experiments. (See also "Self awareness movement" above).

T.A itself was worked out by Eric Berne and his famous book:

Games People Play - Penguin Books, (reprinted 1982):-

gives an insight into human behaviour which is often exaggerated in chronic ill health. This is difficult to read, but full of excellent stuff.

Transactional Analysis for Social Workers and Counsellors:
An introduction, by Elizabeth Pitman, Routledge and Kegan Paul, 1984, ISBN No 0-7100-9581-3:-

is easier to read and much more helpful.

Your own reading of TA will help you to understand you own behaviour and the development of your own personality which is absolutely basic if you are to help patients in your life as a doctor so the last book I shall suggest is:

"Why am I afraid to tell you who I am"
John Powell - Fontana Books - reprinted 1983

The book emphasises the importance of the growth of personality in order to make contact with people. It states the fact that unless we are prepared to change and grow our contact with others will be less than good. Incidentally, anything written by John Powell is worth reading.

Bereavement

Bereavement is inevitable. All change is really loss in one form or another. Bereavement is a massive change, but of course the loss of health when a patient contracts a chronic illness like some form of cancer is bereavement. In some cases it is followed by the threat of death and even death itself. To help me cope with bereavement I relate to CRUSE, the National Voluntary Organisation for bereavement care.

The Journal "Bereavement Care" is a marvellous source of ideas about bereavement and about coping with it. A subscription costs £7.50 from CRUSE

126 Sheen Road
Richmond
Surrey
TW9 1UR

The book "All in the end is harvest", an anthology for those who grieve, edited by Agnes Whitaker, is a wonderful source of help in bad times, published by Darton Longman and Todd 1980, is available from CRUSE. There are many publications by CRUSE but this is the one I find most generally helpful.

Good luck in your journey to find a way to make contact with and help the Cancer Patient! It will be a time of growth and development of your self. I hope you will turn into a friendly professional even if your personality type is A! Love of all fellow humans is in the end all that truly matters.

"Love is patient and kind; it is not jealous, conceited or proud, love is not ill-mannered or selfish or irritable; love does not keep a record of wrong; love is not happy with evil, but is happy with the truth.

Love never gives up; and its faith, hope and patience never fail"

1 Corinthians 13 : (4-7)
Good News Bible translation

I would like to hope that in the place of the word 'love' in this quotation we can insert the phrase 'A doctor newly qualified from Leeds Medical School in (whatever year you qualify)".

Please contact me if you want any help.

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21 The Nature of Psychological Healing

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The word *MEDICINE*, in its original, colloquial meaning, refers to the art of healing. Healing includes both the restoration of normal function to damaged tissue, and the restoration of a sense of well-being after experience of subjective distress or malaise. It is interesting to note that while present day medical education contains systematic instruction on processes of histological healing, little or no instruction is given about psychological healing.

This is because the word *medicine* no longer means the art of healing, but refers to the diagnosis, treatment and prevention of disease. The classification of disease used was, until recently, dominated largely by pathological anatomy, and the model was extended to cover those morbid states where no anatomical change is demonstrable: for example, to conditions like migraine, asthma, depression and schizophrenia.

Conditions such as these were given honorary status, as it were, as *bona fide* diseases, and the assumption was made that these conditions can be reduced to the same 'faulty biological machinery' model as is used for ischaemic heart disease or piles. 'Treatment' therefore refers to pharmacological and physical procedures for modifying faulty biological machinery, so that students are taught about drugs and surgical operations rather than about psychological methods for producing well-being. Doctors have thus become biological tinkers, producing psychological, subjective improvements in their patients by using agents which modify the biological aberrations that are supposed to underlie diseased states. Where psychiatry is concerned, the existence of such defects is established by shaky syllogisms, such as the following one:

- (1) Depression is cured by tricyclic drugs.
- (2) Tricyclic drugs modify the deep amine pool.
- (3) Therefore depression is cured by modification to the deep amine pool.

The fallacy here is that the major premiss—'Depression is cured by tricyclic drugs'—is not universally true, since many depressions are equally well cured by placebo, while some are undoubtedly *not* cured by tricyclic drugs. But although the conclusion—that depression is cured by modification to the deep amine pool—is therefore unsound, doctors continue to give major emphasis to tricyclic drugs in the treatment of depression, to the relative neglect of psychological methods of helping depressed people.

Part of the problem seems to be that doctors tend to assume that disease is present whenever patients present to them with illnesses. This is an understandable assumption but it is not always correct, and it certainly leads to

unnecessary prescribing. Since different authors use the words 'disease' and 'illness' in various ways, it would perhaps be clearer if I said what I mean by them. I will follow Scadding by defining a disease as 'The sum of abnormal phenomena displayed by a group of individuals with a specified common characteristic by which they differ from the norm of their species in such a way as to place them at a biological disadvantage'. The emphasis of such a definition must be on functional—that is to say, physiological and psychological—abnormalities rather than on structural abnormalities: since a structural abnormality does not place an individual at a biological disadvantage unless it interferes with function in some way. Illnesses, on the other hand, are distressing subjective experiences which may or may not accompany diseases, and which may occur when it is not possible to demonstrate a disease.

A disease then, is a systematically observed abnormality which places the group of patients possessing it at some biological disadvantage; it is certainly not a 'thing' with an independent existence which mysteriously attacks from without. Further, although an illness may be part of a disease, there is no meaningful sense in which a disease 'causes' the illness which may be part of it. Illnesses, consisting as they do of subjective experiences such as malaise, dysphoria, pain and fatigue, are notoriously susceptible to non-specific aspects of healing procedures such as placebo effects and the doctor-patient relationship.

To return to our earlier example, depression will always be an illness when it is severe enough to distress the patient: but it must be accepted that many illnesses are transient and self-limiting. But where the nature of the mood disorder is such that there is an increased risk of suicide then depression must also be considered a disease, since the individual is at a biological disadvantage.

But in a group of depressed patients, merely because there may be continuity in the epiphenomena of illness, it does not mean that any associated diseases are the same, or respond in the same way to specific therapies. Psychotherapy, faith-healing—and even, for that matter, the non-specific aspects of behaviour therapy—are treatments for illnesses which may accompany diseases of various sorts.

Difficulties arise, however, when purely subjective experiences are reduced to hypothetical underlying physical processes: first, the 'disease' is treated to the relative neglect of the patient who is ill, so that other ways of helping the patient are neglected if they seem irrelevant to the hypothetical underlying disorder; secondly, the hypothetical disease is reified and seen as something alien and bad that has afflicted the patient: something more real than the symptoms on which its existence has been postulated. Finally, the idea that the overlapping syndromes of psychiatric illness are 'really' specific diseases encourages the simplistic notion that they should be 'attacked' with specific treatment. This ludicrous situation was parodied as long ago as 1840 by Johnson:

The lecturer on medicine exhorts the pupil to lose no time in combating the disease. The instant the malady shows itself, "aux armes!" is the cry—we rush to the encounter: driven back at the first attack, we retire but scorn to

yield, and, flourishing our weapons, we precipitate ourselves a second time upon the foe.

A gentleman who had just seen a patient, ordered his assistant to compound a mixture. 'Put into it' he said, 'a little opium, a little arsenic, a little prussic acid, a little strychnia and a little quinine. There' he continued, smiling, 'I call my great guns, and it will be hard indeed if they all miss fire'. Thus, it appears that all this artillery-talk is not mere flourish of metaphor, but has a very evil influence upon actual practice.

Disease is considered an enemy; drugs are held to be weapons, as it were, and physicians are the soldiers who are to wield these weapons for the defence of their compatriots. Hence the sole reliance of the soldier-physician is in his weapon, his drug, which he grasps on the first signal, and never abandons, as long as he perceives a glimpse of victory.

Johnson went on to describe what he called the *moral treatment* of hysteria, but what we should now describe as psychotherapy:

It is evident that the first point which must be gained by anyone who imposes on himself the task of healing the afflicted mind—the first point and the most difficult—is to acquire the esteem and affection of the patient. Unless this first step is satisfactorily made all is hopeless; but this step, once made, the onward path becomes less thorny.

In the clinical sciences, a great deal can be achieved by studying groups of patients, by establishing norms and by finding ways in which one group of subjects systematically differs from another. It is called the nomothetic approach, and it has been responsible for most of the advances that have occurred in scientific medicine since the time of Rudolf Virchow. It is the best way of studying diseases.

The nomothetic approach should be contrasted with the case-history or *idiographic* approach, which alone can help us to understand how illness can have meaning for a particular individual. I would like you to listen to the words of a young neuropathologist who decided to come to terms with the nature of the morbid process in conversion hysteria, and found, rather to his surprise, that he had changed from the nomothetic to the idiographic approach:

Like other neuropathologists, I was trained to employ local diagnoses and electro-prognosis, and it still strikes me as strange that the case histories I write should read like short stories and that, as one might say, they lack the serious stamp of science. I must console myself with the reflection that *the nature of the subject is evidently responsible for this*, rather than any preference of my own. The fact is that local diagnosis and electrical reactions lead nowhere in the study of hysteria, whereas a detailed description of mental processes such as we are accustomed to find in the works of imaginative writers enables me, with the use of a few psychological formulae, to obtain at least some kind of insight into the course of that affection.

These words were written in Vienna in 1892. The young neuropathologist's name was Sigmund Freud.

Since then alienists have become psychiatrists, and no psychiatrist doubts the importance of the detailed case history in helping him to come to terms with the complexities of the individual case. But minor emotional disorders are common, and time is short, so that instead of formulating the patient's illness in psychosocial terms, the busy practitioner assumes a disease, and prescribes a drug for it.

In his book *Awakenings*, the neurologist Oliver Sacks (1973) writes:

We rationalize, we dissimulate, we pretend: we pretend that modern medicine is a Rational Science, all facts, no nonsense, and just what it seems. But we have only to tap its glossy veneer for it to split wide open, and reveal to us its old dark heart of metaphysics, mysticism, magic and myth.

There is, of course, an ordinary medicine, an everyday medicine, humdrum, prosaic, a medicine for stubbed toes, quinsies, bunions, and boils; but all of us entertain the idea of another sort of medicine, of a wholly different kind: something deeper, older, extraordinary, almost sacred, which will restore to us our lost health and wholeness, and give us a sense of perfect well-being.

For all of us have a basic, intuitive feeling that once we were whole and well; at ease, at peace, at home in the world; totally united with the grounds of our being; and that then we lost this primal, happy, innocent state, and fell into our present sickness and suffering. We had something of infinite beauty and preciousness—and we lost it; we spend our lives searching for what we have lost; and one day, perhaps, we will suddenly find it.

Poets have always known of this existential incompleteness: John Donne wrote:

There is no health: physicians say that we,
At best enjoy but a neutralitie,
And can there be worse sickness, than to know,
That we are never well, nor can be so?

The sense of what is lost, and what must be found, is essentially a metaphysical one: a longing for a general change in the quality of existence: for everything to be all right again. It is essentially a magical wish, and it is embodied by a desire for magical therapy, for 'Wondercure'.

It is here that medicine steps in, with its notion that health can be reified, can be somehow turned into factors or elements—fluids, chemicals: things which can be measured and assessed. Health is reduced to a level, something to be titrated or topped up in a mechanical way.

Sacks writes: 'metaphysics in itself makes no such reduction, its terms are those of organisation and design. The fraudulent reduction comes from alchemists, witch-doctors, and their modern equivalents, and from patients who long at all costs to be well'. Sacks does not mention that the modern equivalent of witch-doctors are greatly influenced in their clinical practices by the drug industry, which has a very strong financial interest in Wondercure.

Our need for miraculous cures is betrayed in our nomenclature: vitamins are 'vital amines'; biogenic amines are 'life-giving amines'. The drug industry is even less subtle, with names such as Motival, Allegron, Sinaquan, Optimax and Quaalude to encourage our magical fantasies.

Doctors are not always the reluctant middlemen between the cupidity of drug companies and the magical desires of patients: being merely human, it is difficult to resist the metamorphosis into 'Superdoc'—the physician who, after all, is best suited to prescribe 'Wondercure'. Alas, Superdoc is merely a witch-doctor in modern dress.

Aubrey Lewis wrote that:

Psychiatrists, like other people, used to look for single causes for single diseases: ideas about aetiology were therefore simple, one-eyed, and usually wrong.

Faith in Wondercure is, of course, sustained by the notion that even in the sphere of mental illnesses there are specific remedies for specific diseases.

I have suggested that there is a magical unscientific element in such prescribing, and that there is a hidden agenda to many doctor-patient encounters, with the patient fumbling with some metaphysical complaints while the physician pontificates and tries to fit the patient's symptoms into one of the syndromes taught to him at medical school. Should he fail to be able to do so, he typically loses interest in the case. I would not like you to think that surgeons get off scot-free. The countless normal appendicectomies that are removed up and down the country are not monuments to their diagnostic incompetence, they are testimony to the belief that many people still have in the efficacy of having somebody symbolically remove badness from their bodies. They have their counterparts in the bits of offal magically produced from people's abdomens by the present-day psychic-surgeons in the Philippines, or the worms and bits of bone that witch-doctors produce from patients' bodies by sleight of hand, but which they tell the patient were lodged in their bodies by witchcraft.

You will all have seen patients who have not improved on antidepressants from their G.P. get better on antidepressants prescribed by the hospital. Yet our drugs are no stronger than those available outside, and the idea that we somehow prescribe them better is an understandable piece of vanity largely unsupported by evidence. The cathedral is just a more effective place for prayer than a wayside shrine: we are effective because healing is a matter of hope and expectancy: it cannot be entirely reduced to chemistry.

This brings me, conveniently, to autobiography. My undergraduate teacher of psychiatry was William Sargant. His teaching strongly emphasised the similarity of psychiatric illness to physical disease, and the extreme efficacy of drugs in the treatment of psychiatric illness. Prescribed by him, drugs worked that did not work when prescribed by lesser men. It was no surprise to me when phenazine—known to be highly effective in reactive depression at St. Thomas's—was shown to be no better than placebo when tested by the M.R.C. (Of course, really, we should say 'no worse' than placebo—but we will return to this important point later.) One cannot observe Dr Sargant without being impressed by his power as a psychological healer, and it seemed to me

then, as it seems to me now, that his power derives largely from his faith in the drugs that he uses, and his ability to communicate hope and an expectation of improvement to his patients. Evans-Pritchard (1937) has described how witch-doctors among the Azande indignantly deny that their therapeutic power derives from hereditary magic: they insist that prophetic and therapeutic powers are derived solely from their medicines. In many primitive societies illness is seen as a misfortune involving the entire person: no distinction is made between mental and physical illnesses and any symptom may be attributed to supernatural causes.

In his recent study in New Guinea, Gilbert Lewis (1975) explains that, in the Sepik, illnesses are not distinguished from one another by symptoms or physical signs, since illnesses are classified by their cause; such as one of the many varieties of spirit possession, or sorcery, or taboo violation. Treatment depends on identifying the cause, and since in their view causes are not discernible from clinical signs, exact description of these by the patient was not relevant. Instead, healer and patient work together to agree on the cause of the illness. This, of course, calls to mind the most appalling varieties of modern psychotherapists and behaviour therapists, to whom description of the form of the disorder is irrelevant: all that one needs to do is to prescribe for the imagined cause—a double-binding mother, maladaptive learning, and so on.

Healers in primitive societies who use states of trance as a medium for healing, are called shamans. The shaman may be a deviant person—sometimes a homosexual—who has low status except when his powers are evoked, when he typically arouses respect tinged with awe. His powers may derive from private mystical experiences, or because he himself is a cured patient. When his power derives from an elaborate course of training he typically has high prestige.

The shaman may make his diagnosis by performing certain acts and then offers a remedy which may be a medication or the performance of suitable incantations. His healing power derives from the *patient's expectation of help* rather than from the incantations, since widely different rituals may produce the same effects. The patient expects help in the case of the shaman because he believes him to possess special powers and to be able to communicate with the spirit world. The patient expects help from us because we have undergone an elaborate course of training and understand scientific medicine: but that is not, I think, the whole story. Doctors are perceived as being close to the phenomena of birth and death, they are in command of pharmaceutical and surgical procedures that powerfully affect our biological functioning, and their power partly derives from their being the descendants of the priest-healers. Fortunately for them, patients come to doctors with powerful expectations of help.

Let us consider a single primitive healing ceremony in some detail, concerning the treatment of 'espanto' in a sixty-three year old Guatemalan Indian woman. This was her eighth attack. Her symptoms seem similar to those that would lead a psychiatrist to diagnose an agitated depression. The Indians attribute it to loss of soul.

The treatment began with a diagnostic session attended not only by the

patient but by her husband and a male friend. The healer felt her pulse for a while, while looking her in the eye, then confirmed that she was suffering from 'espanio'. He then told her in a calm, authoritative manner that it had happened near the river when she saw her husband foolishly lose her money to a loose woman, and he urged her to tell the whole story.

After a brief period of reluctance, the patient loosed a flood of words telling of her life frustrations and anxieties . . . During the recital . . . the curer . . . nodded noncommittally, but permissively, keeping his eyes fixed on her face. Then he said that it was good that she should tell him of her life. Finally they went over the precipitating incident of the present attack in detail. In essence, she and her husband were passing near the spot where he had been deceived by the loose woman. She upbraided him, and he struck her with a rock.

The curer then told her he was confident that she could be cured and outlined in detail the preparations that she would have to make for the curing session four days later. She was responsible for these preparations, which involved procuring and preparing certain medications, preparing a feast, persuading a woman friend or kinsman to be her 'servant' during the preparatory period and healing session, and persuading one of the six chiefs of the village to participate with the medicine man in the ceremony.

The ceremony itself began at four in the afternoon and lasted until five the next morning. Before the healer arrived, the house altar had been decorated with pine boughs, and numerous invited guests and participants were assembled. After they were all present, the healer made his entrance, shook hands all around, and a large meal was served. The patient did not eat, but was complimented by all present on her food. Then the healer carried out a long series of rituals involving such activities as making wax dolls of the chief of evil spirits and his wife, to whom the healer appealed for return of the patient's soul, and elaborate massage of the patient with whole eggs, which were believed to absorb some of the sickness from the patient's body. This was followed by much praying by the healer and the chief before the house altar, and by rites to purify and sanctify the house. All this took until about 2.00 a.m., at which time the ceremony came to a climax. The patient, naked except for a small loin cloth, went outside. Before the audience, the healer sprayed her entire body with a magic fluid that had been prepared during the ritual and that had a high alcohol content. Then she had to sit, naked, and shivering in the cold air, for about ten minutes. Finally she drank about a pint of the fluid. Then they returned indoors, the patient lay down in front of the altar, and the healer massaged her vigorously and systematically with eggs, then with one of his sandals.

Finally, the healer broke the six eggs used in the massage into a bowl of water one by one, and as he watched their swirling whites he reviewed the history of the patient's eight 'espanios', pointing out the 'proofs' in the eggs. The sinking of the eggs to the bottom of the bowl showed that all the previous 'espanios' had been cured and that the present symptoms would shortly disappear. The healer pronounced the cure finished. The patient roused herself briefly on the bed and shouted hoarsely, 'That is right'. Then she sank back into a deep snoring sleep. This ended the ceremony and

everyone left but the patient's immediate family.

The patient had a high fever the following few days. This did not concern the healer, whose position was that everyone died sooner or later anyway, and if the patient died, it was better for her to die with her soul than without it. He refused to see her again as his work was done. She made a good recovery from the depression and afterwards 'she seemed to have developed a new personality. . . . The hypochondriacal complaints, nagging of her husband and relatives, withdrawal from her social contacts, and anxiety symptoms all disappeared'.

Like many healing procedures—varying from cardiac transplant surgery to charming off warts or behaviour therapy—cures are held to validate the treatment method, but failures cannot shake it.

The healer provides an explanation for the patient's otherwise frightening symptoms which reassures the patient, since an otherwise mysterious phenomenon—in this case agitated depression—becomes comprehensible.

The healer uses tricks to increase his credibility and validate his magical powers. In this case he tells the patient of an event she did not know he knew, as well as giving her alcohol and carrying out the six eggs trick. (Incidentally, this same procedure is described in the *Malleus Malleficarum* using molten lead dropped into cold water in order to indicate that a patient has not been bewitched.) The medicine is given to the patient when she is drunk, cold and emotionally aroused, and may be expected to have a maximum placebo effect.

Such elaborate healing rituals are an integral part of the culture in which they occur, and they are accompanied by predictions that cure will occur at a later stage of the healing procedure—as in the statement 'your depression won't really lift until you have been taking these tablets for 10–12 days'.

The combination of trickery with the manipulation of expectancy is seen in many different cultures. Let us consider an example from our own:

Recently a patient in Cornwall with severe facial warts was referred by his dermatologist to a wart-charmer, having failed to benefit from orthodox modern medical treatments. The patient started by telling the wart-charmer—who turned out to be a house painter—that he didn't believe in wart-charming. The wart-charmer replied non-committally that that did not matter but he would like the patient to say how much small change the wart-charmer had in his pocket. The patient sheepishly guessed a figure, whereupon the healer took his money from his pocket and examined it without showing it to the patient, or telling him how much there really was. 'I'll take you on: take this herbal medicine and do not shave for three months. On no account examine your beard to see what is happening, and in exactly three months shave off your beard without examining your skin first.' The patient followed these instructions carefully and, as you have guessed, was cured. The combination of trickery designed to increase suggestibility, expectancy and hope is exactly the same as the Guatemalan example.

Evans-Pritchard describes in great detail the tricks used by witch-doctors to apparently remove worms and bones from their patients' bodies which were

thought to have been placed there by witchcraft. Like present day psychiatrists removing conversion symptoms with various dramatic somatic treatments, witch-doctors still believe in the efficacy of procedures they know to be produced by their own trickery.

In the *espanto* example there are elements of confession, atonement, and re-acceptance by the patient's social group. The linkage of confession and atonement with healing is of course still surviving in religious healing procedures today, and can itself be traced to the linkage between disease and transgression.

Finally, many of the more effective healing procedures stir the patient emotionally: in general terms, it seems likely that emotional arousal is beneficial, especially if it is followed by reintegration of the patient within his social group and increases in self esteem.

We have also seen the use of increasing the patient's self esteem—in the Guatemalan example by the patient having her cooking praised. This can be combined with periods of rest in which little is expected from the patient because they are thought possessed (or 'ill', in our terms), followed by re-establishing the patient in her group in a way which may allow her to re-experience rewards for her own activities. These features are well seen in the next example, of the treatment of spirit possession among the Luo of Kenya.

Treatment, which as usual is expensive and involves dancing and feasting, is undertaken by a female shaman who summons the spirit possessing the patient and finds out what it wants. Often the victim has to be temporarily 'hospitalised' in the shaman's home, thus enjoying a pleasant respite from the work-a-day world of the hard-pressed Luo housewife. In the course of the therapy, the spirit agency involved is not so much permanently expelled as brought under control. And once pronounced fit, and restored to the bosom of her family, the wife must henceforth be treated with respect and consideration lest the dreaded affliction recur (Whisson, 1964).

Armed with these thoughts, let us consider events at Lourdes. Over 2 million pilgrims visit each year, including over 30 000 sick who expect, but usually do not experience, cure. However, most of the pilgrims seem to derive psychological benefit from the experience. The pilgrims pray for the sick and the sick for each other, not for themselves.

It is not my present purpose to involve myself in the arguments surrounding the many miraculous cures reported at Lourdes, but rather to draw your attention to some of the features of the healing process.

Apart from the sudden loss of hysterical conversion symptoms, the organic illnesses that respond take some time to do so: the processes seem to be the same as those involved in normal healing, but they are allegedly strengthened and accelerated. Gaps of specialised tissue such as skin are not restored but are filled with scar formation as in normal healing. No one, for example, claims to have regrown an amputated limb at Lourdes. The preparatory period and the fact that the patient seems to become the centre of interest of his group seems to be important, and emotional excitement connected with these preparations and the journey may be essential for cure to occur. Lourdes does not heal those who live nearby. Having arrived, the actual visit to the grotto is a highly

emotionally charged event in a social setting. Like the healing ceremonies of primitive tribes, the events at Lourdes represent a climactic union of the patient, his family, the larger group and the supernatural world by means of a dramatic, arousing, aesthetically rich ritual that expresses and reinforces a shared ideology. The same aesthetic richness was witnessed by the author at Buddhist healing ceremonies in Burma: it is in striking contrast with the institutionalised drabness of outpatient treatment in the National Health Service.

Cure seems to depend on the patient's expectancies—those that 'interpose a strong intellect between themselves and the Higher Power' are not helped. An elegant experiment by Rehder confirms that cure depends on the patient's state of mind rather than on anything the healer does. Three sick patients were chosen—one with chronic gallbladder disease, another with cachexia after major surgery, and a third dying of carcinomatosis. In the first experiment a local faith-healer tried to cure them by absent treatment without their knowledge. Nothing happened. Then Rehder told them about the faith-healer, built up their expectations, and finally assured them that he would be treating them from a distance at a time he actually knew the healer would not be working. Dramatic improvements occurred in all three and were permanent in the second patient.

Summarising, we can say that while anxiety and despair can be lethal, confidence and hope are life giving. In our society the physician validates his power by prescribing, just as a shaman in a primitive tribe may validate his with some trickery during a healing ritual.

I hope that you are beginning to see why I think it would be a pity if the future produced a situation where physicians had become organ specialists and health technicians, and psychiatrists had fully taken over the priest-healer functions. Like a primitive man, I believe body and mind to be indivisible. The physician can no more afford to disregard the psychological adjustment of his patient than the psychiatrist can afford not to understand how the patient's body works.

Although the non-specific factors that I have described so far powerfully induce psychological healing in all disease, where major disease is concerned, specific, non-placebo effects become important. In psychiatry, I have in mind penicillin for GPI, vitamin B for Korsakoff's syndrome, phenothiazines in acute schizophrenias, and tricyclic antidepressants in psychotic depression. It is to the glory of scientific medicine and the nomothetic approach that treatments for these major diseases exist.

No-one with any of these conditions would be well advised to undertake psychoanalysis, go to Lourdes, or visit a faith-healer. But the majority of illnesses are not like these: they take the form of mixed affective states with or without somatic symptoms or certain other, typical patterns of neurotic symptom formation.

For these common conditions patients consult doctors and other health professionals in huge numbers. The help they get is often very real, but I am arguing that it owes most to the non-specific factors already described. An important example of a non-specific treatment factor in our culture is the placebo effect. The first point to make is that placebos—that is to say,

medicines which are inappropriate to the complaint under treatment—can be of three sorts: true drugs, purported drugs and deliberate counterfeits such as the pharmacological drones prepared for drug trials. Giving penicillin to someone with a cold is an example of a real drug used as a placebo, while the many patent medicines—acne cures, virility restorers, blood refreshers and so on—are examples of purported drugs.

Let us consider the case of treating all sore throats, however trivial, with penicillin. Many of those that get better would have done so anyway if they were due to virus infections, so that the patient's sense of security and well-being while on the penicillin must be thought of as a placebo effect. But contained within the population of people who improve may be some people who might have had a mild secondary bacterial invasion if they had not been on penicillin—so here the benevolent effects will only be partly placebo effects—and a few whose sore throats were due to penicillin sensitive bacterial invasion, in whom the good response to the drug were the direct results of the drug itself, rather than placebo effects. And even in these patients, some of their sense of well-being may well be due to the placebo effect of being on an 'active' drug.

The situation seems to me to be exactly analogous to the treatment of depression with tricyclic drugs. Evidence showing that these drugs are effective in the treatment of depression is almost entirely based on hospitalised depressions. Many of the drug trials in general practice do not show that imipramine is any better than placebo. And the vast majority of depressed patients are treated in general practice. Presumably such populations contain a small proportion of patients with a depression helped by tricyclic drugs, but the effect is lost by the sheer volume of the placebo response.

Instead of being upset at the difficulty of demonstrating drug-placebo differences in general practice, we should ask ourselves why patients receiving placebos do so well. We have already seen that no shaman or witch-doctor worth his salt would dream of trying to do without a placebo.

Beecher (1955) has reviewed the remarkable therapeutic power of placebos to relieve subjective distress in conditions as diverse as angina pectoris, post-operative wound pain, headache and cough. About 35 per cent of the population are marked placebo reactors. They are not distinguished from non-reactors by intelligence and not recognisable by off-the-cuff impressions, not 'whiners' or 'nuisances', and not distinguished by age or sex! But they do tend to be acquiescent, to attend church regularly, to think hospital care 'wonderful', and to talk a lot. Placebos administered in hospital, with the patient surrounded by images of authority and care are more effective than when they are taken alone at home. Finally, and very interestingly, their effect is greatest when symptoms—either anxiety, depression or pain—are greatest. Patients with low symptom levels often get worse on placebos.

Before we consider why minor depressions should respond to placebos, I must mention some recent formulations about depression that are not couched in 'deep amine pool' terms. Engel has drawn attention to the affects of helplessness and hopelessness that precede many episodes of major physical illness, and has related these affects to the experience the patients report of feeling 'given up' by those about them, and so entering a state of 'giving up'.

Table 21.1
Non-specific treatment factors in four types of psychological healing

	Native healer	Effective interpretative psychotherapy	Behaviour therapy	'Medical model' psychiatry
<i>Universal</i> Expectancy of cure	+	+	+	+
Explanation leads to reassurance	Elohoratic: Spirit possession, Taboo violation, etc.	Elaborate: hood experiences	Elaborate: Defective learning experiences	Medical diagnosis passes as an explanation
Increased suggestibility	+	+	+	+
(i) trickery	+	0	0	Reserved for hysteria
(ii) placebos	+	0	0	Active drugs typically used as placebo
Rituals	++	++	++	+
Increased expectancy leads to hope	+	+	+	Essential: 'Power of scientific medicine, etc.'
<i>Optional extras</i> Emotional arousal	variable	usual	variable	variable
Catharsis	variable	usual	unusual	variable
Increased self-esteem	variable	usual	usual	often absent

frightening psychological experiences is rather more difficult than jumping to facile conclusions and recklessly starting some arbitrary treatment programme. Somatic and behavioural reductionists alike may scoff, but it is rather difficult to do well, although fatally easy to do badly. It requires a combination of empathic characteristics which are not easily learned, careful interviewing skills and a fair amount of time.

Compared with the other three classes of healer, psychotherapists have difficulties in using their often complicated explanations of symptoms in a way which reassures the patient, and in particular builds up the expectancy that change will occur as a result of the visits to the healer. Native healers do not doubt their ability to remove symptoms, somatic psychiatrists do not doubt the power of their drugs, and there is no confidence like the Brave New World optimism of the behaviour modifiers. But psychotherapists often doubt. And doubt is soon communicated to the patient.

Psychotherapy can be likened to a journey on a lake in a small boat. Ideally, the patient should be rowing and the therapist should be steering, and there should be a mutually agreed destination. In ineffective psychotherapy—which is, of course, one of the commonest varieties—the destination is not stated, so the rudder is unnecessary, and there is often not any prior agreement about who—if anyone—should be doing the rowing. There may not even be any oars. In either case, the boat drifts aimlessly in the dynamic mists. The patient may not be reassured by the interpretations which he is offered as explanations of his symptoms, and there are no increases in self esteem. Worst of all is the development of hopelessness, which may affect both parties, and which is the enemy of constructive change.

Effective psychotherapists—and I have known many of them—are those who can instil hope and produce an expectancy of change in their patients. They can usually best achieve this by working towards stated behavioural or experiential goals. I would argue that a good psychiatrist is someone who has a mature appreciation of the scope and limits of the major specific therapies—both somatic and behavioural—but who otherwise can practise the non-specific skills of the effective psychotherapist.

I have dealt so far with four classes of psychological healer, but anyone who supposes that general practitioners and physicians spend much of their time prescribing specific treatments for objectively demonstrated diseases is naive. Often the disease is objective enough but the specificity of the treatment for it seriously open to question. And quite often both are pretty vague.

Since not all doctors possess the skills of the effective psychotherapist, yet emotional disorders susceptible to non-specific treatment effects are so common, it is perhaps fortunate that the principles of psychological healing described so far apply to simple doctor-patient encounters in which the doctor apprehends some disorder and prescribes a pill for it. An advantage of this simple version of the medical model not usually acknowledged by its sociological detractors is that it contains within it the strong expectancy that the patient will take the medicine and get better. It is also very easy for the doctor to do.

Why not encourage doctors to explore the psychosocial circumstances that are related to minor affective disorders, and discourage them from prescribing

pills.' There is no doubt that medical educators should do this but it is most improbable that doctors will stop prescribing.

As we have seen repeatedly, prescription of a placebo is part of healing rituals all over the world. The obvious solution—the preparation of a phoney drug Richard Asher described as 'Mist oculi mei cum Betty Martini' is quite impracticable, since it would be instantly exposed by a public-spirited TV documentary within a week of being released. So it would seem that we will continue to use real drugs. One advantage of prescribing dangerous drugs such as tricyclics is that it increases the doctor's sense of competence and self-assurance: he feels, often wrongly, that he is doing a valuable therapeutic job—'fighting' disease, and so on—and this will undoubtedly enhance the placebo responses he produces.

Fortunately, those few severe depressions which benefit from tricyclics probably get them, while finally, the many others who benefit from a placebo response get that too.

It therefore seems to me to be likely that production and sales of 'wondercure' are likely to be very buoyant in the foreseeable future.

I will end by asking you in what ways are modern doctors superior to native healers? Certainly, we prescribe more active drugs than they do—although the vast majority of prescriptions are for symptomatic medicines, tonics, placebos, minor tranquillisers and sedatives. When we treat pneumonia with an antibiotic, diabetes with insulin, or surgically remove an early carcinoma, we are certainly doing what no native healer could do. But the majority of doctor-patient encounters are not like this, and it ill behoves us to allow the panoply and glitter of scientific medicine to blind us to the primitive realities concerning how psychological healing occurs.

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3 Doctor-patient skills

PETER MAGUIRE

Introduction

When a patient seeks medical help the doctor's first task is to ensure that he behaves in a way which leads the patient to trust him and disclose why he has presented, otherwise the doctor may not determine the true nature and extent of the patient's current difficulties. Once the doctor has made a diagnosis he has to discuss this with the patient and explain any action he plans to take. Unless he does this adequately the patient will probably feel dissatisfied and fail to comply with advice or treatment.

The patient may be extremely worried about the possible diagnosis, investigations and treatment. His fears can be allayed only if the doctor is able to clarify exactly what they are and reassure him. The history, physical examination and investigations may reveal a potentially life-threatening or fatal illness. The doctor has then to decide whether, when and how to break the news to the patient and close relatives. Failure of the doctor to correctly identify what they wish to know about the disease and prognosis may hinder their attempts to cope and lead to serious psychological problems. Doctors can discharge these important tasks effectively only if they possess the relevant skills. Unfortunately, many do not appear to acquire them during their professional training.

Deficiencies in history-taking skills

Medical students

Studies of medical students have found that they experience considerable difficulty when obtaining a history of patients' presenting

complaints and commonly fail to explore relevant psychological and social aspects (Maguire and Rutter 1976). Direct observation of interviews conducted by fifty senior medical students found that these difficulties stemmed from a lack of certain essential skills.

Each student was asked to obtain a history of the present illness or problems from a patient previously unknown to them. They were allowed fifteen minutes for this and told that they should try to end their interviews on time. This time limit was imposed because it approximated *much more closely to the time they would have when qualified than the hour or more they were usually allowed for interviews. Only those patients who were likely to be helpful to the students were chosen. All of these were recovering from a depressive illness or an anxiety state. Students were informed that the aim was to establish their level of interviewing skills and that this would be done by recording the interviews on videotape and rating them.*

Subsequent analysis showed that the students lacked essential skills. 86 per cent were too willing to accept data from their patients that were very imprecise. Consequently, they failed to establish when the patients' problems had begun or the relation between these problems and factors which may have triggered them. They were similarly vague about any treatments the patients had received, even though most patients would have told them if asked the appropriate questions. Almost as many (80 per cent) were noticeably reluctant to ask about patients' marriages, other personal relationships, social life and sexual adjustment even when these were relevant to a proper understanding of their problems. When patients spontaneously raised such matters, as most did, the students seemed not to hear them or tried to move them on to more neutral topics.

Most patients used medical jargon when describing their presenting complaints. Few students (8 per cent) attempted to clarify just what the patient meant by words like 'anxiety', 'heartburn', 'depression' and 'diarrhoea'. Consequently, many students gained a false idea of what was wrong with their patients. Most patients gave several clear verbal clues about the nature of their presenting complaints within the first few minutes of the interview. For example, one patient mentioned that she had been experiencing 'pains in my chest', feeling 'out of sorts' and 'sleeping poorly'. The student concentrated on her descriptions of pain and proceeded to clarify these. Although the patient often repeated that she had felt 'out of sorts' and had been 'sleeping poorly' he continued to focus on her pains. Consequently, he

failed to realize that her main problem was a depressive illness and not her chest pains, which had no organic basis.

Shortage of time is often given by doctors as a reason for their failure to identify their patients' problems. It was striking, therefore, that 72 per cent of students wasted much of the available time through unnecessarily covering the same topic several times. Even when the students successfully obtained the relevant information it was often confused and contradictory. This was partly due to the students' reluctance to clarify just what the patients meant. When one woman mentioned she had been suffering from diarrhoea the student assumed she meant loose, runny stools and attributed it to the anxiety she was also experiencing. However, her anxiety was due to her observing blood and mucus in her stools.

Over half (54 per cent) of the students found it difficult to keep the patient to the point. They often allowed patients to talk at length about matters unrelated to their presenting problems despite the 15-minute time limit. When they tried to interrupt to bring the patient back to more relevant matters they did so only tentatively or half-heartedly. They seemed afraid to intervene in case they upset their patients. They often reacted to the patients they could not control by becoming restless, bored or irritated. This usually confused and upset their patients. Only 10 per cent were able to end their interviews in the time allotted.

Only a few students (8 per cent) asked questions in a way which avoided biasing the answers they were given. Nearly a quarter (24 per cent) asked such lengthy and complex questions that patients did not know which component to respond to. Even ordinary social skills were often absent. Only a fifth of students explained exactly who they were, their status or which clinical team they were attached to. Few bothered to ensure that their patients were at ease before they began to ask questions about their main complaints or heeded indications that the patients were distressed. Some students behaved in a way guaranteed to inhibit their patients. They adopted a 'machine-gun' mode of questioning or were far too detached and disinterested. Many found it difficult to take notes and look at the patients. They were sometimes so busy writing down what was said that there was very little eye contact. Their patients got little indication, therefore, that what they were saying was acceptable and worth talking about.

The students' behaviour indicated strongly that they expected their patients to be suffering from only one main problem, whether

physical or psychiatric. They generally assumed that the problem was more likely to be organic than psychological despite the psychiatric setting in which they were conducting their interviews. Very few students followed a predictable sequence of questions, apart from those directed at a review of the major physical systems of the body. Nor was it possible to discern any consistency in the way they began, conducted or terminated their interviews. There was often little connection between consecutive topics and it seemed more often a matter of chance which areas they covered. Only rarely did they try to establish how any problems had affected the lives of their patients and their families.

Similar deficiencies were found by Helfer (1970) when he used simulated parents of sick children to assess the interviewing skills of senior medical students. He noted that they used techniques which hindered the collection of relevant information, relied on leading questions, used unfamiliar medical jargon, cut off patients' communications and neglected to pursue important psychological and social aspects.

Junior hospital doctors

When 145 interns and residents were observed while they conducted 15-minute interviews and physical examinations a similar pattern of problems was noted. Patients were asked too many questions and not allowed to tell their stories in their own way. Consequently, they were reduced to giving monosyllabic answers to direct questions. Attempts at clarification were few and the onset, cause and precipitants of the key complaints were rarely established. The doctors commonly ignored any questions asked by the patients (Weiner and Nathanson 1976). Studies of general medical patients have suggested that junior doctors usually avoid asking them questions about their mood, reactions to their illness or its effect on their families.

Experienced hospital doctors

When Korsch, Gozzi and Francis (1968), used audiotape recordings to monitor a series of over 800 consultations between paediatricians, sick children and their mothers they found a considerable number of deficiencies. Only 24 per cent of mothers believed that they had been able to mention their real worries about their child during

the consultation. Although they had usually tried to do so, the doctors appeared uninterested and failed to realize what the mothers were attempting to disclose. Most mothers, therefore, gave up trying.

Over half the doctors used complicated medical words which the mother did not understand. They wasted much unnecessary time through needless repetition or getting into unhelpful battles with the mother. Many even failed to introduce themselves before they asked questions and a substantial proportion were perceived by the mothers as cold and uncaring.

This failure of doctors to respond to cues given by patients or relatives about their main concerns was also found in a study of communications between surgeons and women attending a breast clinic. Although most (95 per cent) of those who had rated themselves as very distressed on a self-rating scale just before the consultation gave clear verbal or non-verbal clues that they were upset, these were heeded and clarified in only 5 per cent. In 20 per cent of cases the surgeons appeared to have realized that the woman was worried but dealt with it by bland general statements such as 'Don't worry, there's nothing to be bothered about' or 'We'll sort it all out for you'. In the remaining 70 per cent there was no evidence that they had picked up the cues. Only rarely did any of the surgeons enquire directly about how the women had reacted emotionally to the discovery of breast disease and possible cancer. Consequently, many of those who had been distressed before the clinic were just as distressed afterwards (Maguire 1976).

This failure of doctors to enquire systematically how patients and relatives are adapting psychologically and socially to serious physical disease may partly explain why so much of the associated psychiatric morbidity remains hidden. In a recent study of patients who underwent mastectomy for cancer of the breast, the surgeons detected only a fifth of those who had developed psychiatric problems. They also commonly failed to realize the extent to which women were suffering pain, swelling and disability in the arm affected by surgery or adverse physical toxicity when treated with cytotoxic drugs (Maguire, *et al.* 1980a).

General practitioners

General practitioners often argue that they are in the unique position of 'knowing' their patients and there is little risk of missing any physical or psychiatric morbidity which presents to them. However,

direct observation of general practice found a wide variation in the ability of individual practitioners to detect psychiatric illness (Marks, *et al.* 1979). Some identified as few as 20 per cent of those affected while others recognized as many as 80 per cent. Importantly, there was a strong correlation between their detection rate and the use of certain history-taking techniques. Those who asked their patients about their families, and how they were getting on at home and also asked questions designed to elicit the presence or absence of psychiatric symptoms and were responsive to verbal cues had a much better recognition rate. This ability to recognize problems was not related to the amount of time the GPs spent in consultation.

Other broader and larger observational studies of general practice have claimed that many doctors use an inflexible style of history-taking and do not respond to the varying needs of different patients. They tend to focus on the first symptom offered and do not bother to probe any further. They seem unwilling or unable to enter into any real relationship with the patient and seek to prevent or stifle any expression of feeling (Byrne and Long 1976). Although many patients 'offer' their problems to their GPs, the GPs miss most of these and are sometimes so controlling that they stop patients talking as soon as they are about to say anything significant. They often seem to lack an understanding of their patients' lives.

These deficiencies do not appear to be remedied by experience. Irrespective of experience, GPs are found to use few empathic statements, avoid eye contact and do not talk about personal issues. They end their consultations poorly and pay little heed to psychological and social issues (Verby, *et al.* 1979). They are especially likely to ignore psychosocial aspects when patients have established physical disease or present with physical symptoms.

When the patient presents with an obvious psychiatric problem GPs are likely to miss any concurrent physical illness. Thus in a study of 200 patients consecutively admitted to a district general hospital psychiatric unit, physical illness was diagnosed in 33 per cent. This had been recognized before admission in only half of these cases (Maguire and Granville-Grossman 1968). This suggests that GPs, in common with other doctors, assume that patients will have either a physical or a psychological problem. Once they have decided which it is likely to be they cease to probe for the other type.

These studies of medical students and doctors clearly show that there is a consistent lack of certain key history-taking skills which

is not compensated for by greater experience or postgraduate training.

Lack of skills in the exposition

There has been much less study of the ways doctors give patients information and advice about their disease and treatments. Even so, there is considerable indirect evidence that many doctors are equally deficient in these skills.

Surveys of patients in hospital and the community reveal that many feel dissatisfied with the amount of information they are given about their condition and treatment. They commonly complain that they did not understand what their doctor said to them and had insufficient opportunity to ask questions and discuss any worries. In a study of general practice only 18 per cent of social class 1 and 6 per cent of social class 5 patients said that their doctors were good at explaining things to them. In hospital studies the proportion expressing dissatisfaction with the information given has ranged from 5 to 65 per cent (Ley 1977).

In view of these findings it may not be surprising that, on average, 50 per cent of patients fail to comply with medical advice and treatment. For example, even insulin, which could be life-saving for diabetics, was found to have been taken in the wrong dose by half of them. Moreover, 34 per cent had no knowledge of how to test their urine and so had no proper basis on which to estimate the dose. Poor compliance with advice and treatment has been linked to perception of the doctor as business-like rather than warm and friendly, neglect of psychological and social aspects of illness, lack of feedback from the doctor, poor explanation of diagnosis and failure to meet patients' expectations. It represents a major problem in medical practice, since it renders much of the offered treatment and advice ineffective.

Inadequate preparation for major investigative and surgical procedures

These deficiencies in the explanations given to patients have been especially apparent in patients undergoing major investigations or surgery. They have complained that they were not given enough information beforehand and that this made them much more fearful than they would otherwise have been. It has caused some patients to

claim that they would not have agreed to surgery had they fully realized what it entailed. Inadequate preparation has been commonly given as an explanation by patients who fail to adapt psychologically to major surgery such as mastectomy or colostomy.

Doctors find it especially difficult to communicate with patients who are diagnosed as having cancer. There is commonly a serious mismatch between the patient's wish for information and the doctor's willingness to provide it. Many doctors still take refuge in a set of rules such as 'I tell those I believe can take it and don't tell the others'. Their decision about whether or not to share the diagnosis with the patient then depends on their judgment of the patient's capacity to cope rather than on the patient's own wishes, even when these are openly expressed. Thus when one doctor was asked 'Have I got cancer?' by a patient, he elected to lie and say no. He justified this by saying 'I did not think he really wanted the truth - I am sure he wanted to believe he was all right'. Ironically, the patient had already realized that he had cancer, through talking to other cancer patients on the ward. He had given several obvious clues that he knew but these were ignored. Doctors may also go against the patient's wish to know by agreeing with the relatives' request that they should not be told.

Difficulties in communicating with the dying and bereaved

Studies of patients dying in hospitals or at home have found that many of their problems continue unabated because they are not recognized by their doctors or disclosed by the patients. Even problems like nausea, breathlessness, pain, anxiety, depression and mental confusion, which cause much distress to patients and relatives, are often unknown to the doctors (Clartwright, *et al.* 1973). There has been little systematic study of how doctors relate to the recently bereaved. However, it seems likely that they often feel inadequate when called upon to do so, especially when faced with strong feelings of sadness or hostility and when they feel upset by the death.

Why skills are inadequate

Inappropriate methods

Most medical schools and postgraduate training programmes continue to rely on the time-honoured apprenticeship method. Medical

students and trainees learn through a series of attachments to different consultants or general practitioners. They are expected to observe them at work as well as interview new and old patients on their own to establish their key complaints.

Their skills in taking histories are usually judged on the basis of their written or verbal reports which they present in seminars or on ward rounds. And yet the way they perform in these settings often bears no relationship to how they related to their patients. It is most unlikely, therefore, that any deficiencies in their history-taking skills will be brought to light and remedied. In these circumstances students will probably not show much gain in their skills, and this has been confirmed in recent studies. Students taught to take psychiatric histories by the apprenticeship method failed to improve their skills (Maguire, *et al.* 1978).

While methods used to teach history-taking skills are clearly inadequate, this is even more true of the approaches used to teach the giving of advice and information, the preparing of patients for investigation and surgery and communicating with seriously ill patients, the dying and the bereaved.

Inappropriate model

At the beginning of their work with patients students are usually given printed handouts to help them learn the questions they must ask to elicit their patients' physical complaints. These do not often include items designed to help them elicit social or psychiatric problems. Nor do they include detailed discussion of the techniques which the students should use to put their patients at ease and encourage them to disclose their problems. Instead, it seems to be assumed that students already know how to begin and end their interviews, even though they are not normally expected to limit the time they spend with patients to that which will be available when they qualify. It is also assumed that they can establish good rapport, keep patients to the point, pick up and clarify verbal and non-verbal cues, avoid jargon and probe about more personal matters.

When teachers discuss history-taking they heavily emphasize the questions about physical illness. Most neglect psychological and social aspects and may actively discourage their students from probing in these areas. Their emphasis on organic illness may explain Helfer's finding that medical students become less able to cover psychological aspects as they progress through medical school (Helfer 1970).

Most teachers have themselves been trained by the same apprenticeship model. They are, therefore, unlikely to realize that they are deficient in at least some history-taking skills and do not represent as appropriate a role model as they would like to believe. Nor will many of their students realize this. If they are later presented with more appropriate models by psychiatrists or general practitioners they are likely to reject them because they differ considerably from those originally presented. Even when more useful models of history-taking are offered they do not often include discussion about how to assess information needs, provide information and advice. Instead, students usually have to deduce the best methods from watching the 'experts' at work.

Few 'experts' appear to be aware of the considerable literature on factors that enhance patient comprehension, recall, satisfaction and compliance. Thus, when they talk to patients about their condition they pay little if any heed to the value of giving the most important information first, presenting different kinds of information separately, limiting the amount of data given and clarifying the patients' perception and attitudes about their problem (Ley 1977). They often overestimate the patient's knowledge of anatomy and commonly use medical terms, but underestimate their knowledge of disease and treatment. Thus few students are given an appropriate example of how best to communicate with their patients; more commonly they will be exposed to teachers who spend little time giving patients information and advice and prefer to stand at the end of the patients' beds when talking about them.

Doctors' preparation of patients for major investigation and surgery also often neglects the need to first clarify what patients know or fear about what is to happen. Instead, patients' attempts to broach their worries through statements like 'I'm frightened I'll not survive the anaesthetic' are usually met with bland reassurances that there is no risk.

The lack of effective role models is even more evident in the area of communicating with the seriously ill, especially cancer patients. Students and trainees are usually presented with dogmatic rules about telling and not telling. They are only rarely shown how to establish what such a patient desires to know. Few students are given guidelines about how to talk with patients who are dying, or the bereaved. Indeed the more complex and demanding the skills and understanding required, the less likely they are to have been taught them. These

deficiencies in the training offered by most medical schools have been evident for some time. It is, therefore, worth considering why training in these skills has been neglected.

Reasons for neglect

Doctors are assumed to possess these skills

Many doctors believe that they already possess the necessary skills in communication. They argue that this must be so because most of their patients appear well satisfied with the care they give. However, this view ignores factors that commonly prevent patients from expressing any dissatisfaction directly to their doctors.

Patients are clearly dependent on their doctor for advice and treatment. If they complain the doctor may perceive them as ungrateful and give them a lower standard of care than he would otherwise have done. He might even refuse to offer any further treatment and suggest that they consult someone else. Moreover, doctors are usually extremely busy. Patients are loath to take up valuable time on complaints lest the doctor neglects the problems they want help for.

Many hospital consultations are conducted in crowded clinics where the conversation can be overheard by other staff or patients. This can be especially inhibiting to patients who are considering whether or not to voice any dissatisfaction. Even if they are interviewed in more privacy, other medical and nursing staff are usually present. Consequently, patients often feel outnumbered and at a considerable disadvantage. Most doctors come from middle-class backgrounds. Patients from less advantaged backgrounds may feel diffident about complaining because they feel there is a social distance between them and the doctors and have difficulty finding the right words.

When patients do try to complain directly, it is such an uncommon event that the doctor may take it personally and react with hostility. More commonly he will try to brush it aside, jolly the patient out of it or justify his behaviour, as in the following example:

A 45-year-old single woman felt extremely bitter when she believed she had been unnecessarily persuaded to have a breast amputated to remove a cancer of the breast. She expressed her feelings to the surgeon concerned who replied that he had had to perform the

operation to save her life and she had been in no state to decide for herself. She found it very difficult to adapt psychologically to the loss of a breast.

It has been argued that doctors deliberately withhold information from patients to maintain their power over them. Whatever the merits of this view, few doctors appear to check systematically if their patients are satisfied with the care they are being given. Nor do they usually monitor the extent to which patients comply with their advice and treatment. Since few doctors ever receive any real feedback about their behaviour it is easy to understand why so many insist that their skills in communication are adequate; and yet this lack of feedback can have serious consequences.

In a study of women undergoing a course of drug treatment for cancer of the breast most experienced very unpleasant side effects, including depression, nausea and vomiting. Only a minority reported this to the doctors concerned. Some had feared that if they did so the drug on which their lives might depend would be reduced in dose or stopped. Others believed the side effects were inevitable and could not be treated. The lack of detailed probing by the clinicians was another contributory factor to this low rate of disclosure. Unfortunately, there was a strong link between this non-disclosure and the failure of women to complete the potentially life-saving treatment (Maguire, *et al.* 1980b).

Similarly, when the needs of dying patients were investigated by retrospective interviews with their close relatives it was found that few had mentioned problems with confusion, anxiety or depression, because they believed that there was little the doctor could do to relieve their suffering (Cartwright, *et al.* 1975).

Doctors cannot acquire them

Even when doctors accept that there could be some deficiency in communication skills within the medical profession they usually exempt themselves. They believe that 'You were either born with them or you were not' — these are not the kinds of skill that can be learned; deficiencies cannot, therefore, be remedied. Yet there is now considerable evidence that many of these skills can be taught.

Students who were asked to practise interviewing patients under conditions of a strict time limit and videotape recording and then

given feedback about their performance showed a substantial gain in several essential interviewing skills. These included the ability to pick up and clarify verbal leads, help the patient keep to the point (control) and ask about more personal but relevant matters such as marriage, sexual adjustment and the possibility of suicidal ideas (Maguire, *et al.* 1978).

A similar acquisition of skills occurred when beginning medical students were shown videotapes demonstrating how to interview and then given a chance to practise them systematically (Maguire, *et al.* 1977). Feedback techniques have also proved of considerable value in teaching interviewing skills to general practitioners. More personal qualities such as the ability to convey that you understand how the patient feels about his predicament (empathy) have also been taught successfully (Poole and Sanson-Fisher 1979).

While it is already clear that interviewing skills can be learned through more effective methods of training, the extent to which the skills used in giving advice and information can be taught has yet to be established. Similarly, although there have been attempts to teach communication with cancer patients, the dying and bereaved, these have yet to be properly evaluated.

Using these skills will create problems

The practice of clinical medicine is a stressful occupation. Doctors continually deal with the seriously ill, chronically disabled and dying and are ultimately responsible for the care of their patients. Their reluctance to accept the need for training in communication skills may be linked to their need to survive these pressures.

If they communicate effectively with their patients they are going to be confronted with the emotional effects of the illness, their advice and treatment. For example, a doctor whose work includes the treatment of leukaemia has to use extremely unpleasant drugs to try to eradicate the disease. These may cause enormous suffering to the child and his or her parents. If the doctor tries to consider such effects he may feel upset and question the advisability of continuing treatment. He also knows that if he stops treatment the child will die. If he specializes in this area he will have to treat many such children and will often encounter this dilemma. How often can he afford to be upset in this way?

He will also have to come to terms with the fact that many of these

children will die. If he has established a good rapport with a child and family and communicated effectively with them he will be likely to experience the child's death as a personal loss. How many losses can he suffer and yet continue to be effective in treating children with leukaemia?

Doctors confronted with such potentially distressing situations may unwittingly distance themselves from the effects of illness and treatment. They may do this simply by not asking questions about them. Instead, they focus on the physical well-being of the child and assume that unless the patient or relatives complain all must be well. This need to survive emotionally may also account for doctors' reluctance to probe about psychological and social aspects of disease. Doctors and medical students readily acknowledge that they feel inadequate when called upon to ask patients about their marriage and sexual adjustment or pursue the possibility of psychiatric or interpersonal problems. They find it difficult and taxing to break the news to patients who have a potentially fatal illness or are dying. Patients who express considerable anger, bitterness or despair also provoke much unease and uncertainty in the doctor. Patients who refuse to accept the doctor's advice, suffer from chronic disability, are worried about their illness but have a trivial problem, who are adolescent, or present with their spouse are recognized as arousing considerable anxiety in the doctor (McNamara 1974, Bennet, *et al.* 1978). It would be surprising if students and doctors did not try to avoid these more demanding situations.

The skills are assumed to have no important effect on care

When faced with the evidence that many skills in communication can be taught effectively some medical educators still question the need for such training. They argue that these skills have no important effect on the care given to patients or its outcome, and there is some justification for this view.

Over the past decade many teachers have described the introduction of courses in communication skills and claimed that they are effective. However, few have attempted to establish that the use of these skills has any effect on their clinical practice. Thus on common-sense grounds teachers may argue that the ability to pick up verbal cues from patients and clarify them are important skills and should be taught; however, their use may not affect the adequacy of diagnoses.

patient satisfaction, compliance and adaptation to major investigations and surgery.

Although those who advocate the teaching of communication skills need to make more effort to determine the validity of particular skills some progress has already been made, particularly with history-taking and interviewing skills. Senior medical students who acquired history-taking skills through systematic practice and feedback of performance were able to obtain much more accurate and relevant information about their psychiatric patients' problems than students who did not learn these skills (Maguire, *et al.* 1978). Since the history alone allows doctors to establish the true diagnosis in 83 per cent of medical patients the potential importance of this improvement in history-taking ability is obvious (Hampton, *et al.* 1975). The students may have gained their additional information by behaving in ways which upset the patient. For example, they might have adopted tough interrogation methods. However, when medical students were taught these skills at the beginning of their training by watching demonstration videotapes and practising history-taking, those who used the desired skills were perceived by the patients as more likeable, empathic and effective than those who did not (Maguire, *et al.* 1977).

While training medical students in history-taking skills leads to more accurate diagnosis and greater patient satisfaction in the short term, it is not yet clear whether these effects last or if they are generalized to other settings than the one in which the students were taught. Thus the students may apply these skills when they know they are being observed but fail to do so when they are not observed. They may practise them while doing a clerkship in psychiatry but not use them at all in subsequent clerkships in general medicine or surgery. Work by Poole and Sanson-Fisher (in press) found that students who had been taught how to be empathic 3 years earlier showed a definite decline but were still considerably better than students not taught this skill. This suggests that training in communication skills ought to continue throughout their clinical years.

A recent study by Goldberg, *et al.* (1980) has been especially encouraging. They set out to teach American trainees in general practice how to interview so that they could better recognize and diagnose psychiatric disturbance. They used a combination of demonstration videotapes, practice through role-play, practice with real patients and videotape feedback of performance to achieve this aim. They found strong correlations between the doctors' ability to detect

were suffering from chronic bronchitis were much less likely to have recovered their respiratory function and returned to work if they perceived exercise as worthless and dangerous, work as dangerous and stressful and themselves as vulnerable (Rutter 1979). Training in history-taking skills could undoubtedly enable doctors to identify these attitudes better. Studies could then be carried out to determine whether these attitudes could be modified and whether this improved recovery.

There have been few attempts to train medical students and doctors systematically in the skills required to promote patients' recall and compliance with advice and treatment but the results of some experimental studies have been encouraging (Ley 1977). Four general practitioners were asked to read a manual which was designed to help them improve their ability to provide information and advice. This advised them to give instructions and advice at the beginning of the information-giving sequence and stress their importance. They were asked to use short words and sentences and present information in separate and explicit categories. For example, they should have said 'I am going to tell you: what is wrong with you; what tests will be needed; what will happen to you; what treatment you will need; and what you must do to help yourself. First, let me say what I think is wrong with you.' Their patients recalled between 61 and 80 per cent of the information given by their doctors when they used these methods. This was significantly more than the 52-59 per cent of data they recalled when these methods were not used.

Better comprehension and recall should lead to better compliance, and there is some support for this view. Women who wished to keep to a low-carbohydrate diet were given a leaflet which was either very easy or moderately easy to read and understand. The simpler leaflet resulted in more weight loss. A similar effect was found when 160 psychiatric outpatients were given one of three leaflets giving them information about the antidepressants or tranquillizers they were to receive. The leaflet that was most difficult to read was typical of those often given. The other two were especially designed to be easy or moderately easy to read. Compliance was assessed on the basis of pill counts. The 'difficult' leaflet was ineffective in promoting compliance but medication errors were much fewer in patients given one of the other leaflets.

These studies suggest that doctors could substantially improve recall and compliance if they avoided presenting information in a

psychiatric disturbance and their use of their newly acquired skills. These skills included the following: establishing good eye contact with the patient at the beginning of the consultation; the appropriate handling of case notes; the use of an appropriate degree of control to help the patients disclose their problems; helping the patient focus on the present rather than the past; clarifying verbal and non-verbal cues which patients give about their problems; and demonstrating empathy.

In another study a nurse without any psychiatric experience was trained through systematic practice and audiotape feedback of performance to use a similar range of skills to monitor the progress of women who had undergone mastectomy for cancer of the breast. She also had to be taught how to avoid blocking the patients' communications by jollyng them along or trying to reassure them before she had established what was wrong with them (Maguire, *et al.* 1980a). She was subsequently able to recognize and refer for help 83 per cent of those of her patients who developed psychiatric problems. The doctors, social workers, nurses and general practitioners who were looking after an identical group of women and had not received any such training could identify only 22 per cent of those of their patients who had been similarly unable to adapt to the diagnosis of cancer, its treatment, or both. Consequently, there was four times more psychiatric morbidity in the group not followed up by the nurse.

The main focus of these studies was on psychiatric illness. The extent to which the detection of physical illness could be similarly improved by training in the relevant skills has yet to be properly determined in patients suffering primarily from physical illness. Even so, when the medical students mentioned earlier obtained more information as a result of training this applied equally to psychiatric and physical problems. Similarly, the specially trained nurse also detected more of the physically-based problems which patients developed after mastectomy. These included: pain, swelling and disability in the arm affected by surgery; recurrence of the cancer; and adverse effects of the potent drugs given to some of the women.

The emphasis on eliciting psychological aspects of patients' problems may also prove to have beneficial effects on prognosis and rehabilitation. Patients who suffer high levels of anxiety and depression are less likely to recover from their physical disease or return to a normal life-style. Attitudes to their disease and work as well as self-image may also affect recovery. For example, patients who

complex or difficult form, realized that most patients lack elementary technical knowledge and checked to see whether the patient had any misconceptions. Claims that doctors who are friendly, clarify patients' views and expectations about their disease and treatment, and spend time talking about non-medical matters obtain greater patient satisfaction and compliance still need to be tested experimentally.

Preparation for major investigation and surgery

The systematic provision of information and support to patients who are to undergo surgery or special investigations appears to have beneficial effects (Ley 1977).

Egbert, *et al.* (1964) compared a control group who received only the care routinely given with patients who were also told what pain to expect, given instruction about postoperative exercises and visited more regularly by the anaesthetist. The experimental group recovered sooner, required fewer analgesics and was discharged earlier. In another study Schmitt and Woodbridge (1973) compared the effects of routine preoperative care with those of giving information, advice and clarifying any worries or misconceptions. The experimental group were much less anxious, were discharged sooner and showed less physiological disturbance than control subjects.

These and other similar studies which have found a positive link between preoperative preparation and outcome of surgery have used several approaches at once. It is, therefore, still not clear what contributions of the ability to provide needed information and support and to clarify and correct misconceptions before surgery make to this improved outcome. Moreover, the beneficial effects have so far been shown only in relation to less serious surgery. Indeed, in a recent study of the effects of providing advice and information before mastectomy it was found that while the women welcomed this help, it did not prevent the later development of psychological and social problems (Maguire, *et al.* 1980c).

Other work has suggested that whatever approaches are used, they should be tailored to the individual needs of the patient. Patients who were experiencing low levels of anxiety were actually harmed by the presentation of a leaflet which told them about the surgical procedures which were shortly to be performed. Patients who had high levels of anxiety benefited from the leaflet (Klos, *et al.* 1980). Patients who cope by not facing the outcome of their disease and its

implications may fare less well if forced to accept information. Those who cope best by knowing about what is to happen to them and why may be hindered if information is withheld. Skills in assessment are clearly required if doctors are to determine how patients best cope.

Most attempts to improve preparation of patients before surgery have relied on specially trained nurses. The extent to which surgeons and anaesthetists could acquire the relevant skills and would apply them routinely to their patients has still to be determined.

Talking with the seriously ill, dying and bereaved

Some educators have introduced courses or workshops designed to teach medical students and doctors how to communicate with seriously ill patients, especially those suffering from cancer, the dying and bereaved. They have usually emphasized the use of listening skills, clarification of the patients' feelings, needs and wishes, and the importance of being alert to verbal and non-verbal cues. Without rigorous evaluation of these courses it is not possible to say if they achieve their objectives and also benefit patients and relatives. However, there is no doubt that many doctors feel especially inadequate when confronted with these situations and would welcome some training.

Recent work by Hinton (1979) suggests that willingness to communicate more frankly with patients who are dying leads to a reduction in their anxiety, depression and irritability. Moreover, he found that patients preferred this openness and appeared less troubled by thoughts of dying and more prepared to discuss it than patients who had been spoken to less honestly. Attempts to counsel those bereaved people who are at high risk of developing psychosomatic or psychiatric illness have also had encouraging results (Parkes 1980). They appear to reduce the risk of a poor outcome to that of low-risk groups. Therefore, it would seem worth while to give doctors and medical students more training in the relevant skills.

The priorities of modern medicine

When some of those concerned with medical education are confronted with this case for teaching skills in communication they dismiss it immediately, arguing that the main task of the doctor is to diagnose and treat disease, especially physical illness. They consider

that social and psychological problems merit much less attention because they are not based on any underlying scientific theory. From this perspective, general medicine and surgery are perceived as based on 'hard' science while psychiatry and psychology are 'soft' and, therefore, less relevant subjects. This bioengineering ideology has dominated medicine for a considerable time and led to increasing emphasis on the technology of medicine rather than the patients being treated and their families. Thus suggestions that teaching in communication skills should receive more attention are likely to be resisted on the grounds that the curriculum is already overcrowded and if any additional time is made available this ought to be allocated to general medicine and surgery.

Recently, there has been a hint that the pendulum may be beginning to swing back. Many more studies have been conducted into communication between doctors and patients and much concern has been expressed about their inadequacy. Doctors, patients and families alike have also become increasingly worried about the impairment in the quality of life that often results from modern treatments. Only systematic training in skills in communication is likely to redress the balance.

Towards more effective training

Identify deficiencies

If teachers are to properly understand the difficulties that their medical students and doctors experience in attempting to communicate with patients it is important that they first identify the exact ways in which they are deficient. This can most easily be done by asking the student or trainee to take a small tape-recorder with them when they are called upon to interview a patient, give information or advice, prepare patients for investigations and surgery, or talk with the seriously ill, dying or bereaved. If they explain to the patients that they wish to assess how well they communicate with them the patients will probably not object. Indeed, they are much more likely to cooperate and give the student or doctor valuable feedback about their performance.

It is usually very threatening to receive feedback about actual performance, since it exposes strengths and weaknesses which cannot be dismissed as due to the teacher's prejudice or invention. A teacher

who takes the trouble to monitor how well his students perform before any training will be much more understanding of their difficulties and less critical of their performance.

Development of adequate models

Attempts to analyse deficiencies will also help in the preparation of guidelines about what the student or doctor should be trying to communicate and how they should communicate it. Such models should be quite explicit about the skills to be learned and provide clear operational definitions of them. Such specification of skills will also enable performance to be properly assessed.

Measurement of performance

If training is to be effective teachers must be able to assess performance reliably. They can do this accurately only if they have received some training in the use of appropriate rating scales or rely on ratings made by others.

The simplest approach is to use global rating scales to assess the extent to which students or doctors use specified skills during an encounter with a patient. Thus a five-point scale (0-4) was used to assess medical students' ability to respond to verbal cues. A score of '0' meant that they showed no ability to respond to verbal cues, while a score of '4' indicated that they were extremely good at this. Ratings using such scales were able to obtain a high level of agreement about a student's performance. They also maintained their own rating standards over time (Maguire, *et al.* 1978).

Simpler skills, such as introducing oneself by name, could only be rated as present or absent and ratings of these were almost totally reliable. Although this type of rating system can be learned easily by teachers, its validity has not been determined. Thus it is not yet clear how well such global ratings validly reflect the number of times the student or doctor used particular behaviours.

Other teachers have preferred to assess performance by analysing each item of behaviour and classifying it as belonging to one of a series of predetermined categories. They have usually based such judgments on transcripts of the interview. However, simplified versions have been developed which can be completed as the interview proceeds. Thus the observation schedule developed by Morrison and Cameron-Jones

(1972) for use in general practice included the following ten items: salutation, reassurance, invitation/initiation, encouragement, command, direct question, problem resolution, symptoms, problem-related expression and questioning. They were able to construct profiles for each trainee on how often they used each of these categories of behaviour. Byrne and Long (1976) also favoured this approach and distinguished between behaviours which were doctor-centred, patient centred or negative. Both the global and item-analysis approaches offer students and doctors reliable measures of their performance and affects of training. No direct comparison has yet been made of the two approaches in terms of their effects on the learning of skills.

Method of training

The first decision a teacher must make is how best to present the skills to be learned. Merely presenting printed handouts can be effective but using television to demonstrate the skills in action is likely to be more so. If teachers have the necessary resources to make their own material they may wish to do so. Alternatively, they may wish to use videotapes made for more general distribution. For example, the Association of University Teachers in Psychiatry has produced a series of tapes which demonstrate basic interviewing skills. Such tapes may illustrate the use of the correct skills (modelling) or discuss the advantages and disadvantages of using other behaviours. They can be presented to large groups or watched individually by medical students or doctors.

Once the mode of presenting the desired skills has been decided the teacher has to determine how best to help the student or doctor acquire the skills. It is crucial that the trainee has a chance to practise the desired skills and is directly observed while doing so. Since direct feedback by a tutor about performance is relatively ineffective the practice of skills should be recorded on audiotape or videotape. The trainee can then see for himself exactly how he performed.

The tasks set the trainee should approximate closely to those which he will meet in clinical practice. Thus, if he is going to have only five minutes available for consultation it is important that at some stage he is given only five minutes to see how he handles such time limits. Some teachers may prefer to begin by asking trainees to practise only one skill at a time and limiting discussion to that (microcounselling).

Others present trainees with a whole group of skills to be practised. Both are effective but it is not clear if either method is superior to the other. It could also be that some skills are easier to learn than others. It would then be sensible to teach these first.

Practice conditions

Trainees may practise with other trainees or the teacher (role-play) with real or simulated patients. The advantage of simulators is that the level of complexity of the problems they present can be matched to the trainee's training needs and they can give valuable feedback about how they felt the trainees went about their task. They also avoid the risk of exposing real patients to unskilled trainees. This may be especially important when attempting to teach the skills of communication with the seriously ill, dying and bereaved (Sanson-Fisher and Poole 1980).

Despite the attractions of using simulators there could be disadvantages. Students and doctors may learn less efficiently than if they practise with real patients and the simulators could conceivably be harmed by their experience. While studies are needed to clarify these issues, training could combine all three methods. Trainees could begin by clarifying the desired skills through role play and then progress to practise with simulated patients. Finally they could practise with real patients.

Mode of feedback

Feedback via television or audiotape replay both result in significant learning of interviewing skills but audiotape recording and replay is the much cheaper method. It would seem sensible, therefore, to use audio-recording to help students and doctors achieve a reasonable level of skill. Videotape recording and replay could then be used to sharpen up these skills and focus on non-verbal behaviours.

Attempts to encourage students as individuals or in small groups to teach themselves through watching videotape replays have proved disappointing (Maguire, *et al.*, unpublished observations). They learned much less than students who were given feedback individually or in small groups by a supervisor. The presence of a supervisor enables trainees to understand better the skills being taught and realize what their strengths and weaknesses are. It also leads to them enjoying training more.

Since the provision of individual feedback is time consuming it is encouraging to find that when students are taught in small groups of four they fare as well as when taught individually by a supervisor, even though only one of their interviews is discussed on each occasion. Therefore, training large numbers of medical students or doctors through systematic practice with real or simulated patients and then giving them audio-feedback of performance within small groups in the presence of a supervisor is workable.

Who should teach

Most attempts to formally teach skills in communication have been made by interested individuals or departments. Some medical schools have invited behavioural scientists, especially clinical psychologists, to run special courses, usually in the preclinical years or during the students' introduction to clinical medicine. In other schools, departments of medicine, paediatrics, general practice or psychiatry have carried the burden of such teaching. Rarely has more than one department been involved in any medical school.

These attempts have usually been effective in the short term but they suffer from several disadvantages. As long as the need to train in these skills is propounded by a minority of departments, students may see them as being of limited importance. Their newly acquired skills may decline during subsequent training, especially if when they try to use them they are discouraged from doing so. They may try to use them only when they talk with the kinds of patients they originally practised with.

Similar disadvantages usually apply when the training is carried out by departments which have been specially created to teach skills in communication, for the students practise in these departments using role play and simulators rather than in the outpatient clinics or on the wards. If these departments were given sufficient personnel and resources they could attempt to integrate their teaching with that carried out by the clinical teams. They could also have access to the students at several points during their training and move from simple to more complex skills.

Perhaps the most effective method would be to train ordinary medical teachers within different departments to carry out this training and to regard it as a continuing commitment. The extent to which they could and would do this has yet to be determined. However, each

registrar or senior registrar who is already concerned in clinical teaching could be asked to do this. Since students are seconded to them for some weeks they could each take a group of four. Each student would be given an audiotape recorder and asked to record an interview with a patient he has been asked to see. The students could then meet for an hour with the tutor and the interview of one of the students would be discussed. The remaining three students would be advised to listen to their own tapes in the light of what was discussed. For the next three weeks the other students' tapes would each be discussed.

As the students move through their different attachments the tasks could cover history-taking, giving information, advice, preparation for investigation and surgery, and talking with the seriously ill, dying and bereaved.

Conclusion

Serious deficiencies exist in the communication skills of many medical students and doctors. Methods of training have been developed which can remedy these. The major challenges facing those concerned with teaching these skills are how to carry this out on a large scale, how to overcome the continued resistance of some medical educators and the need to demonstrate even more clearly that the skills being taught benefit patients in tangible and important ways.

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BIBLIOGRAPHY FOR "BREAKING BAD NEWS" COURSE

Prepared by Dr Lesley Fallowfield

Teaching

During the workshop for the facilitators of the "Breaking Bad News" course we will be employing the same teaching methods that will be used when teaching the course to students. Particular emphasis will be given to the use of role-play, and simulated/standardised patients together with audio and video feedback. The annotated bibliography which follows contains key references to all these teaching methods. The list is selective and is by no means comprehensive but may be sufficient for the needs of clinicians involved in teaching the course. It would be helpful if participants made suggestions about suitable references to include in a bibliography for students. Interested participants on the course might benefit initially from reading some general articles on communication skills in clinical medicine such as:-

Lipkin, M. Quill, T.E. Napodano, R.J (1984) The Medical Interview: A core curriculum for residencies in internal medicine. *Ann. Int. Med.* 100; 277-284.

This paper was written by the members of the Task Force on the Medical Interview in the US. This provides useful references for anyone involved in course design for medical students and junior doctors.

Lipkin, M (1987) The medical interview and related skills in Branch WT. *The Office Practice of Medicine*. Philadelphia: W.B. Saunders Co; Chapter 76.

This splendid chapter gives a comprehensive overview of the functions of a medical interview. It includes some insightful descriptions of the impact that patients' different personality styles may exert on the interview and describes the interaction from both the patient and the doctor's perspectives. It provides an excellent introduction to communication skills in general written by an experienced 'front-line' clinician.

Maguire, P (1990) Can communication skills be taught? *Br. J. Hosp. Med.* 43: 215-216.

This extremely brief but persuasive paper, written by one of the foremost researchers in communication and medical education answers the question posed in its title in a coherent manner which should satisfy even the most cynical.

Role-play

Maguire, P. & Faulkner, A (1988) How to do it. Improve the counselling skills of doctors and nurses in cancer care. Br. Med. J. 297; 847-849.

This brief paper (the last in a series of 3 which are all worth reading) describes the short intensive workshops run by the author to help doctors and nurses improve their interviewing, assessment and counselling skills. There is a succinct, useful description of how to facilitate such a workshop together with some helpful guidance about conducting effective role-play sessions.

Cohen-Cole, S.A. Teaching with role-play: A structured approach in Lipkin M, Putnam S and Lazare A (eds) The Medical Interview. New York: Springer-Verlag in press (1991).

This excellent chapter, shortly to be published, provides a coherent description of the benefits and possible pitfalls when using role-play with medical student groups.

Audio and Video Feedback

Maguire, G.P., Clark, D. & Jolley, B. (1977) An experimental comparison of three courses in history-taking skills for medical students. Med. Educ. 11: 175-182.

Maguire, G.P. et al (1978) The value of feedback in teaching interviewing skills to medical students. Psychol. Med. 8: 695-704.

Both of these early papers by Maguire and his colleagues show the value of giving feedback to students on their interviewing skills.

Maguire, P., Fairbairn, S. & Fletcher, C. (1986) Consultation skills of young doctors: 1 - Benefits of feedback training in interviewing as students persist. Br. Med. J. 292: 1573-1578.

In this paper the authors reassess the interviewing skills of doctors 5 years after they had received conventional training or training with video feedback as students. It shows that benefits persist over time in the interviewing skills of the video-feedback trained group.

Ende, J (1983) Feedback in clinical medical education. J. Am. Med. Ass. 250: 6; 777-781.

In this interesting article the author provides valuable guidelines drawn from a large literature in a variety of disciplines on how to give effective feedback in a clinical medical setting.

Ethics of Video-Recording

It is, of course completely unacceptable for anyone be they a learner, patient, or even an actor to be video-recorded without their prior consent. In practice very few patients will refuse when asked. A good account of the ethics involved and examples of consent forms for video-recording can be found in:-

Pendleton D. et al. "The Consultation: An approach to learning and teaching". 1990. Oxford Medical Publications, Chapter 9.

Simulated/Standardised Patients

McAvoy, B.R. (1988) Teaching clinical skills to medical students: The use of simulated patients and videotaping in general practice. *Med. Educ.* 22: 193-199.

In this well-written paper the author describes the use of simulated patients with video feedback in a 5 week general practice course for medical students at Leicester. It shows the advantages of such teaching, in particular how valuable the process is for increasing medical students' communication and diagnostic skills in comparison to the more traditional, didactic methods of teaching clinical methods.

Stillman, P. & Swanson, D (1987) Assessing clinical skills of residents with medical school standardised patients. *Ann. Int. Med.* 105; 762-771.

This article describes the use of stimulated patients in teaching and assessing the clinical skills of under-graduates and graduates in the United States.

Breaking Bad News

There are no easy ways of breaking bad news but the manner in which serious information is communicated can enhance or disrupt an individual's ability to assimilate and adapt to the news. The following articles are all good examples taken from a variety of specialties.

Woolley H, Stein A, Forrest G C, & Baum J D (1989) Imparting the diagnosis of life threatening illness in children. *Br. Med. J.* 298; 1623-1626.

This interesting paper reports interviews with parents of 70 children with either terminal or life threatening illnesses. It shows how parents "valued an open, sympathetic, direct, and uninterrupted discussion of the diagnosis in private that allowed sufficient time for them to take the news in and for doctors to repeat and clarify information." Evasive interviews were especially disliked. The long-term impact of how the news was broken may still preoccupy parents many years later. The authors provide useful data and helpful guidelines on 'how to do it.'

Sophie (Society of Parents Helping in Education) 'Shared Concern' Kings Fund. (1987). London.

This excellent short booklet was written to accompany the video 'Shared Concern' but it is well worth a read in its own right. The authors outline the typical reactions of parents to the news that they have a baby with a disability and provide clear suggestions and guidelines on the communication of distressing information and means of ameliorating the emotional trauma.

Forrest G. (1989) 'Breaking bad news' to children in paediatric care. In Couriel J (ed) *Breaking Bad News*. Duphar Medical Relations. London p10-16.

This short, helpful chapter describes the meaning that death has for children of different ages and discusses the emotional implications that news about life-threatening illnesses may have for children and their parents. It contains some interesting anecdotal accounts of children's reactions and means of reducing their stress.

Slevin M.L. (1987) Talking about cancer: How much is too much? Br. J. Hosp. Med. July; 56-59.

In this succinct, insightful paper Slevin discusses the fact that doctors who have difficulty coming to terms with their own emotional reactions to serious illness and dying often have the most difficulty in communicating about these issues with patients. He outlines the barriers poor communication about cancer create for the patient and his/her family and the doctor. He also discusses the various merits of truth-telling, in particular dispelling the myth that it is reasonable to tell the family but not the patient that they have cancer.

Goldie, L (1982) The ethics of telling the patient. J. Med. Ethics. 8; 128-133.

In this sensitively written paper the author discusses the problems created for families communicating with patients who have not been truthfully informed about their diagnosis. It provides persuasive arguments against doctors colluding with relatives in keeping bad news from patients; and demonstrates the psychological damage caused by failing to facilitate discussions between partners before death. "... couples instead of growing together, whither in each other's arms."

Maguire P & Faulkner A (1988) How to do it. Communicate with cancer patients: I Handling bad news and difficult questions. Br. Med. J. 297; 907-909.

Maguire, P. & Faulkner, A (1988) How to do it. Communication with cancer patients: II Handling uncertainty, collusion and denial. Br. Med. J. 297; 972-974.

These two basic papers give actual examples of dialogues between patients with cancer and their doctors. Suggestions about handling difficult questions are given and may provide useful starting points for seminar discussion with students.

Hogbin, B. & Fallowfield, L.J (1989) Getting it taped: the 'bad news' consultation with cancer patients. Br. J. Hosp. Med. 41: 330-333.

Lack of information or not being told what is wrong are common complaints voiced by patients. In cancer this can greatly increase the stress and anxiety experienced yet many doctors still withhold information on the grounds that patients' will find it too emotionally distressing to be told the truth. In this paper 46 patients with cancer were given audio-tape recordings of their 'bad news' to take home. Subsequent analysis of questionnaire data revealed that both patients and their families benefited enormously from and appreciated the opportunity to hear details of their diagnosis and treatment again. Interesting quotations from patients show that honest, frank communications ameliorate anxiety and instil confidence in the doctor.

Fallowfield, L.J (1990) "The Quality of Dying" in The Quality of Life: The missing measurement in health care. Souvenir Press. London. Chapter 8.

In this chapter I describe some of the evidence, both empirical and anecdotal, that dying patients prefer to be told the truth. The chapter contains references to some useful further reading and includes a discussion about doctors' own fears about death. Some students also may find that Chapter 3. 'The Quality of Life in Cancer', contains some helpful references and further discussion about the contribution that lack of information about the diagnosis makes to psychological distress.

LEADING ARTICLES

Rationalism versus irrationalism in the care of the sick: science versus the absurd

Since the dawning of medical history, the care of sick persons has been determined by two powerful and opposing attitudes of mind, the rational and the irrational or, in other words, the scientific and the non-scientific. The dominance of one or the other in any society or in any period of history has been dictated by the prevailing philosophy, social anthropology and cultural determinism. It is my intention to illustrate that the distinction between orthodox and alternative medicines is not one of establishment versus antiestablishment, but one of science versus the absurd, and that the subject which is portrayed so poignantly in this issue of the Journal (page 710) by Lowenthal is merely a timely reminder that the cultural dominance of empirical science in this century is in danger of being eclipsed by the "new age" counter-culture of irrationalism.

Rationalism and irrationalism coexisted in the mists of antiquity as judged by the decoding of the Edwin Smith Papyrus and the hieroglyphics on the temple walls at Karnak.¹ The rational ancient Egyptian physician writing in the Edwin Smith Papyrus distinguished malignant tumours from inflammatory masses and recognized the natural history of the former and the futility of any medical intervention. In contrast, the priestly physicians of the cult of Imhotep (the first surgeon to become deified in his own lifetime) prescribed complex magical rituals for the treatment of similar diseases.²

Early in the classical Grecian period, the founding father of Western medical rationalism, Hippocrates, separated medicine from magic.³ His descriptions of internal diseases are classics to this day and, in casting out hypothetical evil spirits as a satisfactory explanation for disease, he set the scene for the empirical approach to the development of effective medical intervention. Sadly, the dominance of his philosophical approach was shortlived when the teachings of Aristotle gained ascendancy.

Aristotle taught that all disease was a result of an imbalance of the four natural humours — blood, yellow bile, black bile and phlegm.² He also taught an inductive philosophy which encouraged the avid search for corroborative evidence in favour of any speculation arising from his construct of the universe.

In the second century of the current era, Galen reintroduced the authority of Aristotle and taught that inflammatory diseases were a result of an excess of blood, which, therefore, should be treated by venesection, while malignant disease was caused by an excess of black bile (melancholia) which, of necessity, should be treated by diet and purgation.² Such was the force of his teachings and the dominance of his personality that the practice of "orthodox" medicine became fossilized for 1600 years, buttressed against doubters by Christian theology.

Throughout the Dark Ages the rationalists were treated as subversives with the flame of rationality in medicine being kept alive by the Islamic and Jewish physicians of the great Arab schools of medicine at Ispahan and Alexandria.^{4,5} This spirit of enquiry and intellectual honesty is reflected in the following two quotations. In 10th century Persia, Avicenna stated "The experimentation must be done with the human body, for testing a drug on a lion or horse might not prove anything about its effect on man",⁴ while Maimonides, from 12th century Alexandria, pre-empted Francis Bacon when he wrote "Teach thy tongue to say I do not know, and thou shall progress".⁵

It is, of course, widely believed that the first challenge to the inductive logic of Aristotle came from the 16th century English philosopher, Francis Bacon,⁶ who warned against the hazards of certainty and made a virtue out of doubt. However, it is more likely that the Anglo-Saxon father of deduction was the 14th century monk,

William of Occam, whose razor-sharp intellect can be summed up by his famous dictum — *Essentia non sunt multiplicanda praeter necessitatem*.⁷

The 15th century not only saw the Renaissance of art in northern Italy, but the dawning of the age of enlightenment in France that ultimately spread across Northern Europe. Michel de Montaigne wrote in his essay on education:⁸

The tutor should make his pupil sift everything and take nothing into his head on simple authority or trust. Aristotle's principles must no more be principles with him than those of the stoics or epicurians. Let their various opinions be put before him. He will choose between them if he can. If he cannot, he will remain in doubt. Only fools are certain and immovable.

Fortunately for Montaigne, he was something of a country gentleman and recluse, because writing in this manner in the late 16th century would have been considered subversive and revolutionary.

Paradoxically, it was during the period of the Renaissance that the word "quack" originated. Quicksilver or mercury was a popular remedy for syphilis and wandering pedlars, who were known as quack-salvers, sold mercury ointments. They would claim that their unguents cured all illnesses.

Perhaps encouraged by this new spirit of enquiry, after some simple clinical observations, William Harvey described the circulation of the blood in 1628.⁹ His observations refuted the ebb and flow model that Galen had described, which was a keystone of medical orthodoxy at that time. He so angered the orthodox establishment that he lost his practice and his livelihood. Furthermore, when the anatomical dissections of Vesalius failed to demonstrate pores that linked the right and left ventricles, which were postulated by Galen, the apologists of this age insisted that the great master could not have been wrong but that nature had evolved within the intervening 1400 years.

Perhaps the nadir of irrational "orthodox" medicine was illustrated by the events that surrounded the death of King Charles II in 1685.¹⁰ Dr Scarburgh, one of the 12 physicians who were called to treat the King, left a sickening description of the excesses that poor King Charles suffered before he was allowed to die of his cerebral haemorrhage. He was cut and bled and drugged with emetic and purgative agents; a plaster of Burgundy pitch and pigeons' dung was applied to his feet, while pearl julep and ammonia were forced down his throat. It is likely that the common folk of this period were better off without physicians, even though their lives were short and brutal.

Early in the 18th century the science of Isaac Newton and the "profane" writings of Voltaire generated a turbulence within the Western world, ripples of which can be felt to this day. In 1734, shortly after the publication of Voltaire's *Lettres philosophiques et elements de la philosophie de Newton*,¹¹ a contract was taken out on his life, his books were burned publicly and he had to go into hiding. Surely an adumbration of the Salman Rushdie affair. By making a virtue out of uncertainty, Voltaire continued in the tradition of Maimonides, Francis Bacon and Michel de Montaigne; minds became unfettered and real medical progress followed.

In 1747, James Lind, a physician in the Royal Navy, conducted the first controlled trial demonstrating that oranges and lemons were an effective treatment for scurvy when compared with five alternative folk remedies.¹² It has been suggested that if the Royal Navy were to have adopted James Lind's finding, then the British Navy would not have been incapacitated by scurvy in 1776 and the North American colonies still would be controlled from Westminster! However, perhaps an even more important revolution occurred in

1798 when Edward Jenner advanced his hypothesis that vaccination might prevent smallpox.¹² At first, Jenner was naturally timid about his proposals and wrote to John Hunter for advice. Hunter replied "Your solution is just, but why think, why not try to do the experiment?"¹⁴ As a result of Edward Jenner's experiment, smallpox virtually has been eradicated.

However, it was not until the middle of the 19th century that the bastions of bigotry began to crumble and deductive scientific empiricism became the dominant influence on medical thinking. For example, in 1834, a Mr Wardrop, writing in *The Lancet*, stated that "The abstraction of blood from the body is one of the most powerful therapeutic means [for inflammatory diseases]"¹⁵ yet two years later Pierre Charles Alexandre Louis carried out the first mathematical analysis of the effect of blood-letting on pneumonia.¹⁶ He demonstrated unequivocally that the earlier that bleeding was commenced, and the greater the volume of blood that was drained, the greater was the mortality of pulmonary inflammatory disease. As this put paid to the central tenet of Galenic doctrine, it was left to the American physician, Oliver Wendell Holmes, to clear the decks of the worst accretions to medical practice that had resulted from 2000 years of tradition: "If all medicines could be sunk to the bottom of the sea, it would be all the better for mankind and all the worse for the fishes".¹⁷

With the slate wiped clean, it now was left to medical scientists to commence innovation in a big way, based on experimentation and deduction, rather than on observation and induction. In 1867, Lord Lister introduced antiseptics as a therapeutic sequel of Louis Pasteur's bacterial theory of infection.¹⁸ Anaesthesia and, later, blood transfusion allowed the explosion in surgical developments within the first three decades of this century. Antibiotic agents and the science of immunology then led to the prevention or cure of most infectious diseases and the development of organ transplantation.

We now come to the current era where the pace of medical innovation and discovery has slowed down. Medical workers have to realize their limitations in dealing with chronic diseases such as cancer, degenerative diseases of the arteries and joints, congenital diseases, neuropathies and myopathies; however, the public is fickle and frustrated. It has come to expect medical breakthroughs on demand in every decade and, with this frustration, we witness the emergence and self-confidence of the irrational schools of medicine, disguised as alternative or "holistic" medicine.

In their attacks on medical science, the proponents of the irrational schools claim that we are trapped within a mechanistic concept of the body as ascribed to René Descartes, whereas they are the only ones who look upon the body and its diseases in a holistic manner. I reject this charge as offensive and nonsensical. We have long accepted that the Cartesian model of a human being can give no satisfactory account of the phenomenon of homeostasis. Yet, there are subtle differences between the type of holism that is practised by modern scientific medicine and that which is preached by practitioners on the fringe of medicine.

The ideas of holism that are described by 20th century irrationalists are completely metaphysical and relate to some as yet undiscovered and, for all we know, non-existent natural life force, whereas in modern scientific medicine our concepts of holism are based on well-defined neuroendocrine pathways which are known to link the psyche and the soma. Furthermore, we can recognize, measure and manipulate the chemical and cellular messages that pass through the body from cell to cell and from organ to organ which, in a healthy state, act in perfect harmony.

I think it is time that we stated loudly and unequivocally that the

only demarcation between modern scientific medicine and "alternative" medicine is that between the hard-won scientific rationalism of the heirs of the age of enlightenment and that of the inductive philosophy of the Dark Ages. In her immensely readable book *Medicine and culture*, Lynn Payer notes how even today the demarcation between orthodox medicine and quackery in Western Europe and the United States is as much determined by culture as by science.¹⁹ Thus, we have the "French impressionist" school of medicine which still is influenced by the teaching of René Descartes, which accepts homoeopathy as part of mainstream medicine, and the German school, which is influenced heavily by romanticism and the anthroposophic system of Rudolf Steiner, with the prescription of tonics and health spas being essential to medical practice. Nevertheless, Payer has the kindest words to say about the practice of medicine in the United Kingdom:²⁰

By far the strongest philosophical movement in Britain has been that of the empiricists Locke, Berkeley and Hume. For empiricists, all knowledge comes from experience, not theory or thought. In contrast to Descartes's plan of evolving the universe from a thought, the British philosopher Francis Bacon urged society to try evolving thought from the universe.

The current controversy about alternative medicine in Australia as illustrated within this issue of the Journal is not some local problem or phenomenon of contemporary life, but another symptom of the virus of irrationalism that is a serious threat to the health and welfare of all nations. Lowenthal well may be described as a reactionary bigot who is protecting the closed shop of orthodox medicine by the mouthpiece of irrationalism; however, we should see him as continuing in the fine tradition of the rational school of thought, which is perhaps the most precious inheritance of Anglo-Saxon philosophy. Let us always remember that a miracle, by definition, is an event that occurs with the greatest rarity. How many cancer sufferers will be denied the proved benefits of modern oncological practice while awaiting the miraculous cure that has been claimed by Ian Gawler?

Perhaps it is appropriate to leave the last words to the Scottish philosopher, David Hume:²⁰

No testimony is sufficient to establish a miracle unless the testimony be of such a kind that its falsehood would be even more miraculous than the fact which it endeavours to establish.

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The case for a real alternative in the treatment of cancer

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IT IS DIFFICULT to enter into the debate on alternative medicine in cancer treatment without immediately engaging in a discussion about definition. There is no accepted definition of 'alternative' medicine. Many practitioners prefer the word 'complementary' and try to avoid a confrontational focus towards orthodox medicine. In addition, the word 'holistic' is now being applied to describe an approach to treatment which is by no means the prerogative of the alternative practitioner and some would say is what good medicine has always been about. The holistic approach does offer a set of concepts that allow for a perspective against which the debate on alternative treatments can be sensibly discussed.

Several articles have outlined the historical, philosophical and scientific basis to the reappraisal that is now occurring within Western medicine (Pietroni 1984) — a summary of the principles of the holistic approach is provided in Table 1.

Table 1: Principles of the holistic approach.

1. The whole is greater than the sum of the parts (Body-Kind-Spirit-Environment).
2. Use of an extended range of interventions, orthodox and 'alternative'.
3. Education as well as treatment (prevention-promotion-anticipatory health-care).
4. Doctor-patient relationship including active participation by patient as well as doctor.
5. 'Physician heal thyself' — health of practitioner influences outcome of treatment.

It is difficult for the traditionally trained doctor to avoid comparing one 'treatment' against another and the clinical controlled trial has been the accepted basis for so doing. However, because many of the 'alternative treatments' are based on an understanding of human functioning which is at odds with the mechanistic, dualistic and reductive assumptions governing much of what we do in Western medicine, the comparisons can prove difficult if not impossible. Again, much has been written concerning the appropriateness of research methodologies for undertaking such comparisons (Heron and Reason 1984).

The major focus that 'alternative medicine' has had on cancer treatment has been to explore the areas of psychosocial and dietary factors in both the causation and manage-

ment of several cancers. The use of other alternative treatments, acupuncture, homeopathy, herbal medicine, will not be described. The most recent expansion of our understanding of the influence of behaviour on immunological mechanisms has indicated that a common language may soon be possible. It must be said, however, that from a conventional viewpoint, one of the problems entering into a debate with alternative practitioners has been their simplified notion of cancer as being one disease. The holistic model allows one to accept many different levels of causation as well as of diagnosis.

Psychosocial factors and cancer

Two excellent review articles (Cunningham 1984; Bahnsen 1979) set out the current state of study in this area, and the idea that personality factors are influential in the causation of cancer goes back to Galen, who noted that cancer was more common in 'melancholic' than in 'sanguine' patients. Those studies which explore the correlations between mental attitude and development of cancer have been of three kinds:

1. Retrospective analysis of patients with cancer, exploring possible links with 'life events'

and comparison with non-cancer patients.

2. Prospective analysis of the impact of mental attitude on the progress of the disease.
3. A few long-term truly prospective studies on psychological attitude before the onset of any disease.

What seems to be emerging from these studies, although all have methodological concerns, is the following hypothesis: a sense of hopelessness and helplessness, together with an inability to express emotion adequately and poor social support, precede the onset of cancer in a significant proportion of patients. The recent studies by Greer have explored the influence that mental attitude has on the progression of cancer and he has demonstrated a more favourable

5-year survival rate amongst patients with responses to their cancer that could be classified as 'fighting spirit' and 'denial' as opposed to 'stoic acceptance' or 'helplessness/hopelessness'. Similar studies in Manchester and London are currently being undertaken to examine this hypothesis further. Before leaving this area, it is interesting to note that those few anecdotal reports on spontaneous regression in cancer all describe what has been termed 'a dramatic existential shift'. This 'shift' involved a resurgence of hope, together with an alternation in belief system and acceptance of responsibility for the process of healing and recovery.

The use of 'psychotherapeutic interventions' in the treatment of cancer, which have largely been the province of the psychoanalysts and alternative practitioners, base their rationale and appeal on the influence of 'spirit' and 'mind' on 'body'. The techniques that have been popularized recently through the Simontons' work include a mixture of breathing and relaxation, meditation, hypnosis, visualization and 'positive thinking'. There is extensive literature from several sources on the psychophysiological concomitants that result from regular practice of the self-help techniques.

The use of meditation has attracted wide support and the long-term beneficial results of the treatment of hypertension with this approach is now well-established (Patel 1984). Meditation can be described as a state of relaxed non-aroused physiological functioning which can help to liberate the mind from disturbing and distracting emotions. Table 2 details some of the alterations that occur both during and after meditation. This technique can be used by itself or together with visualization.

Visualization

This is a technique that involves the suggestion of mental imagery (e.g. a peaceful place — white cells engulfing cancer cells) during a state of relaxation or meditation. A simple analogy of, imagine, a lemon being cut and observing the consequent physiological responses will allow for an understanding of the rationale underpinning this approach. Again, there is an enormous quantity of literature from other disciplines describing its use in several conditions. However, few, if any, adequately controlled trials exists for its use in cancer treatment. A recent evaluation by the American Cancer Society on the Simontons' work acknowledge that 'the approach had some positive effects namely promoting relaxation

Table 2: Psychophysiological changes in meditation.

Pulse rate	↓ 30% (normal)
Blood pressure	↓ 20%
Blood lactate	↓
Gas exchange	↑ O ₂ consumption
	↓ CO ₂ elimination
Prolactin	↓
Cortisol	↓
EEG	↑ Alpha wave
Carotid sinus reflex	↓
Psychological stability	↑
General sense of control	↑

and a sense of control', but found no evidence that it provides 'objective benefit'. They also drew attention to concerns relating to the use of these techniques. These concerns related to patients developing 'guilt feelings' and neglecting the possibility of physical treatments.

It would be fair to say that there is no objective evidence as yet that any of these techniques add to longevity for any one group of patients. However, nearly all studies remark on the improvement in quality-of-life and the relationships surrounding the patient, his family, and his advisors. Even if these approaches do not prove to be effective as specific treatments, it has been salutary for the medical profession to be reminded of the importance of the need for compassion, hope, and listening to the patient. The recent increase in 'holistic cancer centres', hospices and self-help organizations (BACUP) illustrate how important our patients view these issues.

Immunological factors and cancer

It is from this area of research that the majority of conventional practitioners are likely to be convinced of the need to explore the techniques outlined above. The recently published annotated bibliography brings together over 3,000 references from scientific journals on the role of the mind on immunity (Locke and Hornig-Rohan). It is necessary to draw on systems theory to appreciate the link between unhappiness and molecular events leading to neoplastic changes and Engel (1980) has provided much useful work in this direction. Animal experimentation with stress and tumour growth suggest that acute stress that cannot be controlled tends to favour cancer growth: relevant mechanisms included lowering of catecholamines and increase in acetylcholine leading to immunosuppression. The suppression of lymphocyte stimulation following bereavement and studies by Pettingale indicating correlation between serum IgA and mental

attitudes in breast cancer patients add some clinical weight to these animal studies. Further studies suggesting shifts in IgA as result of regular meditation now lend at least theoretical laboratory support for the use of such techniques in cancer treatment.

Diet and cancer

If the debate on the links between emotion and cancer arouses partisan feelings, then that concerning diet is even more polemical, especially when it comes to supplements and megavitamin therapy.

There has always been good epidemiological evidence relating dietary fibre and colorectal cancer. Fibre is known to bind carcinogens and reduces intestinal transit time by a factor of two. Seventh-Day Adventists, whose diet is mostly lacto-vegetarian, have a much lower incidence of cancer compared to the average American.

Known constituents in the diet such as mycotoxins and nitro-zamines have been implicated in carcinogenic experimental studies in animals. Similarly, low levels of dietary fat, and an increase in vitamin C, vitamin E, retinoids, and flavinoids have all been shown to protect against experimental cancer. The biosynthesis of the cellular membrane and the integrity of the endoplasmic reticulum is dependent on the concentration of cellular glutathione which is in turn dependent on adequate dietary intake of these nutritional constituents. Human studies have linked cancer to poor intake of vitamin A and carotenoids, thus the daily dose of carrot juice. Most, if not all, research has focussed on the

constituents of the diet and not on how the food is either processed, cooked or eaten. A recent study in Ohio examining the atheromatogenic influence of high dietary fat for rabbits found a 60% reduction in plaque formation in one group of rabbits eating an identical diet. This group of rabbits were being fed by a different laboratory technician who insisted on taking each rabbit out of its cage, calming and stroking it before it was fed its high fat diet. Saying Grace before a meal may thus have a physical as well as 'spiritual' benefits. Although most doctors would accept a nutritional link for certain cancers, very few will go so far as to examine or prescribe a diet specifically to 'reduce the cancer'. Again, there is no controlled evidence to suggest that this is possible, but we must avoid the type II statistical error of dismissing as unfounded what may in fact be both true and very important, just as our colleagues in alternative medicine should avoid the type I error of accepting as true what has not been proved.

There are various forms of dietary therapy practised by alternative practitioners for cancer and the different approaches include:

- Fasting
- Detoxification
- Purified diet
- Augmented diet
- Macrobiotic diet
- Bristol diet
- Gerson diet
- Pearce diet

Apart from some specific interventions such as a coffee enema, megavitamin therapy, laetrile injections, many of the guidelines suggested by these diets are similar

to those now accepted by most Western nutritionists as constituting a healthy diet. These include the following (Table 3).

Where the alternative practitioners have rightly attracted the wrath of conventional doctors is when their insistence on enforcing a largely unpalatable diet that may take 2 hours to produce, reduces the patient to a sense of guilt, confusion and misery. It must be said, however, that many of us involved in cancer care in conventional settings have been the cause of an equal amount of misery, pain and confusion, and many ineffective, painful and dangerous regimes have been tried on hundreds of unsuspecting patients.

The only real alternative to cancer treatment is for us to approach this area with the degree of humility which reflects our current ignorance both in orthodox and alternative treatments.

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Table 3: Basic guidelines to a healthy diet.

1. Limit sugar intake — this means reading labels carefully — canned foods, bottled sauces, dressings and cereals even if described as 'natural', often contain high quantities of sugar.
2. Avoid highly-processed foods with preservatives and colouring added.
3. Eat natural, whole grain breads, cereals, pasta and rice, rather than highly-processed varieties.
4. Eat plenty of fresh fruits and vegetables, rather than those which are frozen or canned.
5. Eat high-quality protein sources (low-fat dairy products, whole grains, beans, fish, eggs, fowl) and avoid high-fat meat, high-fat cheese, red meat and processed meats.
6. Find suitable beverages to replace coffee, tea and fizzy canned drinks. Try a variety of juices and drink plenty of spring water.
7. Reduce salt intake by avoiding added salt and snack foods.
8. Keep tobacco and alcohol consumption to a minimum and avoid unnecessary medication.
9. Keep fast-food and canteen eating to the minimum.
10. Reduce fried foods both at home and in restaurants. Cook vegetables in a steamer rather than a saucepan.
11. Try to eat your largest meal in the earlier part of the day to ensure the body is able to rest more at night.
12. Give yourself time to eat slowly, peacefully, and with concentration. This way you will be aware when you have eaten enough and will be less likely to over-eat. Digestion is aided by a peaceful body and mind.

Quality of life in cancer patients – an hypothesis

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Author's abstract

Quality of life is a difficult concept to define and to measure. An hypothesis is proposed which suggests that the quality of life measures the difference, or the gap, at a particular period of time between the hopes and expectations of the individual and that individual's present experiences. Quality of life can only be described by the individual, and must take into account many aspects of life. The approach is goal-oriented, and one of test analysis. The hypothesis is developed in a diagrammatic way, and several methods of testing the hypothesis suggested.

'The longer I live, the more I am satisfied of two things... First that the truest lives are those that are cut round-diamond fashion with many facets. Second, that society is always trying in some way or other to grind us down to a single flat surface'.
The Professor at the Breakfast Table. Oliver Wendell Holmes.

In recent years, improvements in cancer treatment have emphasised the importance not only of the short-term, but the long-term implications of therapy. The term 'quality of life' (or more correctly 'good quality of life') is being increasingly used. Because of the cultural and psychological overtones associated with cancer, it is a useful model to use in the study of this topic, though it should not be considered that 'quality of life' is only relevant to the cancer patient. Far from it, the concept is an important one in all forms of illness, as indeed it is in health. The term 'quality of life' extends not only to the impact of treatment and side-effects, but to the recognition of the patient as an individual, and as a whole person, body, mind and spirit. A study of the quality of life is difficult for two reasons. Firstly, there is a real problem in defining what is meant by 'quality of life'. Secondly, even if this were possible, there remains the difficulty of quantifying 'quality of life' and of comparing one individual with another. There is also the related, but equally important fact,

Key words

Quality of life, cancer, task analysis, nursing process, problem-oriented medical records

that measurement may not be important from the point of view of the patient. Action may be required to modify the existing quality of life. Thus measurement and action need to be linked.

Measurement of quality of life

Increasing attention is being paid to the measurement of quality of life in cancer patients. This has ranged from the use of linear analogue scales to assess well-being, mood, level of activity, symptoms, social activities, and anxiety (1), to questionnaires which measure life events (2). Many of the currently used methods are based on life areas or have adopted a task analysis, or problem-oriented approach (3,4,5). Others have emphasised the importance of the subjective aspects of quality of life, and the importance of the patients' perception of their health (6,7). The psychosocial aspects of health have also been studied separately (8). De Bono in his book *The Happiness Pursuit* has used the concept of 'life space' and its development in relation to happiness and quality of life (9). Many attempts have therefore been made to define the quality of life.

The definition used below seeks to put quality of life into perspective from the patient's point of view, as it is the patient's perception which is important. The definition is not claimed to be original, rather it brings together several related concepts. More importantly it may allow the quality of life to be measured and an assessment made of the effectiveness of any action initiated to modify it. The definition given is essentially the statement of an hypothesis which requires to be tested, and which uses the cancer patient as a model for the study of this concept. The aim of this paper is to stimulate discussion on the theoretical basis of measuring and defining quality of life.

A definition of 'quality of life'

The quality of life can only be described and measured in individual terms, and depends on present lifestyle, past experience, hopes for the future, dreams and ambitions. Quality of life must include all areas of life and experience and take into account the impact of illness and treatment. A good quality of life can be said to be present when the hopes of an individual are

matched and fulfilled by experience. The opposite is also true: a poor quality of life occurs when the hopes do not meet with the experience. Quality of life changes with time and under normal circumstances can vary considerably. The priorities and goals of an individual must be realistic and would therefore be expected to change with time and be modified by age and experience. To improve the quality of life therefore, it is necessary to try to narrow the gap between hopes and aspirations, and what actually happens. The aim therefore is to try to help people to reach the goals they have set for themselves. A 'good' quality of life is therefore usually expressed in terms of satisfaction, contentment, happiness and fulfilment and the ability to cope. This definition emphasises the importance of personal growth.

From this definition of quality of life certain implications follow:

- i) It can only be assessed and described by the individual.
 - ii) It must take into account many aspects of life.
 - iii) It must be related to individual aims and goals.
 - iv) Improvement is related to the ability to identify and achieve these goals.
 - v) Illness and treatment may well modify the goals.
 - vi) The goals must be realistic.
 - vii) Action is required to narrow the potential gap. This may be by the patient alone or with the help of others.
 - viii) The gap between the expectation and the reality may be the driving force for some individuals.
 - ix) As each goal is achieved new ones are identified, opening the gap again. It is a constantly changing picture.
- Quality of life therefore, measures the difference, at a particular moment in time, between the hopes and expectations of the individual and that individual's present experiences.

THE DIMENSIONS OF QUALITY OF LIFE

Basic work by Flanagan (4) and others has stimulated the concept of 'life areas'. Such areas cover all aspects of life and can provide a useful checklist which will enable the patient or the caring team to identify those aspects which are of particular importance to the individual. The patient's own problems and priorities can then be identified. Such life areas include: home and garden, work, hobbies, financial problems and body image, diet, mobility, ambitions, spiritual problems, concept of the future etc. The identification of problems and priorities makes it possible to develop realistic goals and to use these to assess progress and measure the reduction of the 'gap'. This allows the hypothesis to be tested by evaluating the effectiveness of the specific intervention.

The representation of quality of life

To develop this concept further a series of diagrams will be used to illustrate the hypothesis

- 1) The hopes, ambitions and dreams of the individual

are shown in the upper line (Figure 1) varying naturally with time. In reality, the here and now, there is also variation, and the gap between hopes and reality may never be bridged. There are periods of good times and bad times. The gap therefore measures the quality of life. For many individuals it is the need to close the gap which provides the driving force of personal ambition and achievement. The activity necessary for narrowing the gap may be associated with as much satisfaction as the end result.

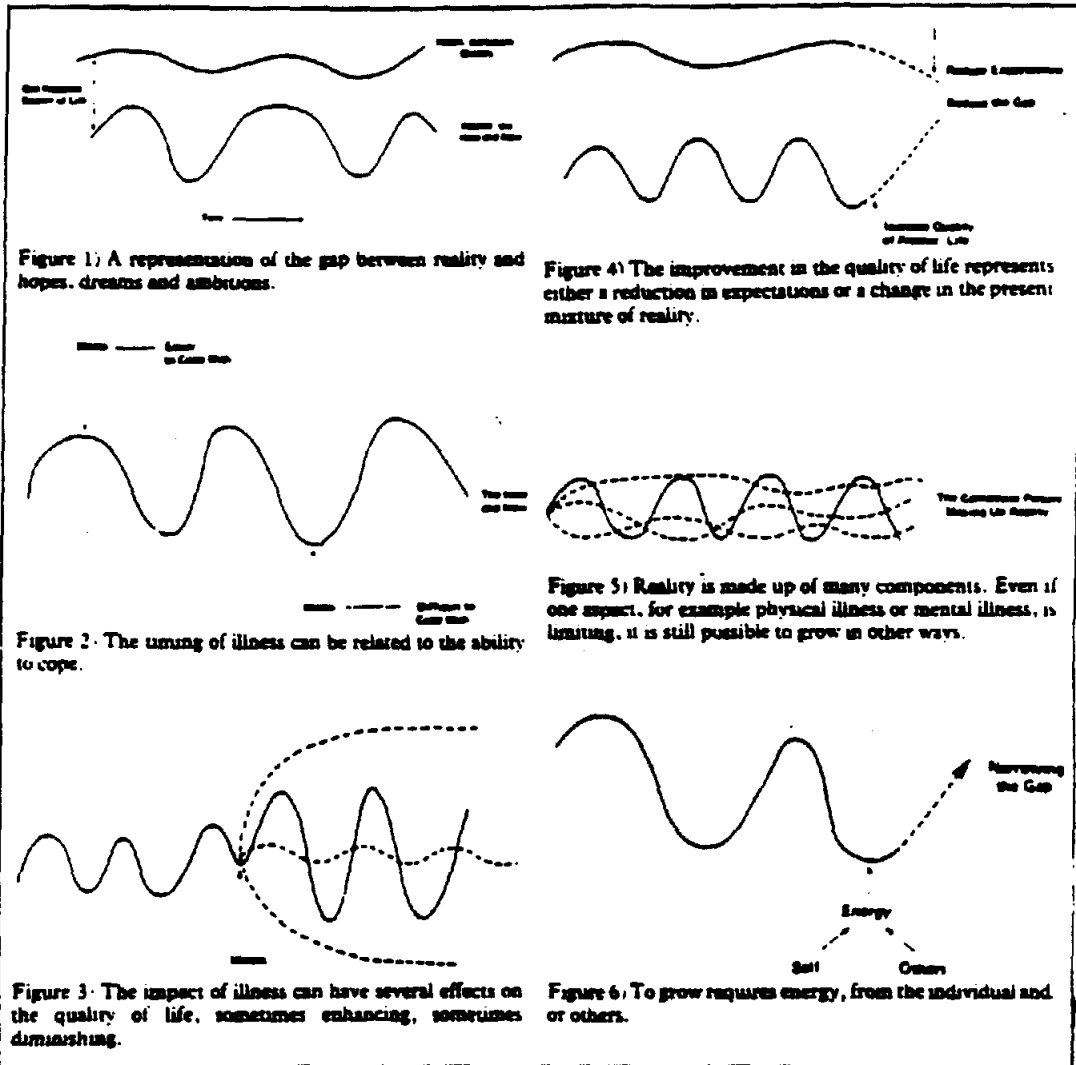
- 2) The impact of illness may vary depending on the time at which it occurs (Figure 2). When things are going well the individual may be able to cope with illness, when they are not, it may be the last straw.

- 3) Illness may modify the quality of life in several ways (Figure 3). For some patients the quality of life may be enhanced, and the so-called 'benefits of illness' may occur. For others the quality of life may be greatly diminished. In some patients following illness, life may be characterized by wide swings in quality with highs and lows, while for others it becomes flat and dull.

- 4) To improve the quality of life it may be necessary either to reduce some of the expectations and ambitions, or to increase the quality of life as it is (Figure 4). To decrease the expectations does not mean denying hope, rather it makes the expectations more realistic. The patient is encouraged to develop appropriate goals. In terminally ill patients for example it may be unrealistic in some patients to continue to pretend that things will improve. For others the denial of this may be crucial in maintaining the quality of life. Hence the importance of individual interpretation of the size of the gap.

- 5) The 'here and now' profile is a composite of many aspects of life and not all need to increase to improve quality and narrow the gap (Figure 5). Illness or ageing, for example, can inhibit further development of a physical nature. Yet the individual can continue to grow and develop in other ways, socially, psychologically, emotionally and intellectually. It follows therefore that to improve quality of life in those who are ill requires a minimisation of physical problems and an enhancement of other aspects of life.

- 6) Some individuals are able, therefore, to have a good quality of life even though they may appear to have major problems, for example serious physical illness or poor social conditions. They are able to achieve this either by reducing their expectations and being satisfied with what they have, or by being able to rise above the problems by personal growth and development. It is not possible to make value judgements about other people's 'quality of life'. It is their own perception which matters. Conversely for some patients, 'trivial' events may have a major impact on life and may be much more important than 'cancer'.



7) To increase the quality of life requires energy to change the height of the wave. This can either be self-generated or come from outside, from others. A variety of methods may be employed (Figure 6).

8. What about the 'man who has everything' yet is unhappy? Two explanations are possible. First, he may still not have what he really wants and still be searching. Secondly, overshooting the hopes may also lead to tension and stress. Over-promotion for example, or in patients an unexpected recovery, may be stressful to all concerned.

9. Could this concept of quality of life be of value to the caring team who may have to make decisions about initiating, or not initiating, treatment? The hypothesis

emphasises the fact that discussion with the patient is the only way to assess patient needs. Secondly, it may help in communicating with the patient when treatments have to be used which may have short-term side-effects but long-term benefits. Thirdly, it allows identification of future events which may be of special significance to the patient (anniversaries, births, weddings etc) when it may be acceptable to induce some side-effects, if short-term survival for a particular purpose is the objective.

In more general terms, could this hypothesis be of value in assisting in other treatment decisions, such as when to resuscitate a patient, or to switch off life-support systems, when the concept of subsequent 'quality of life' may be being considered? Under these

circumstances the use of the diagrams may be of value when discussing this with the caring team, and with the relatives. Because the reality may be seen to be very low, and the subsequent expectations also low it may assist in decision-making in specific circumstances. It may allow an assessment of the size of the gap between the present and future recovery.

Evaluation

The hypothesis as described is essentially a problem-orientated or task-orientated approach to quality of life. As such it is similar to that developed in the *Nursing Process* (10) and in problem-orientated medical records (11). It is suggested that it is a pragmatic approach to the definition of quality of life, its assessment, modification and evaluation. It can be developed in these four stages.

- (i) Assessment. The patient's own list of problems and priorities, the estimation of the 'gap'.
- (ii) Development of a plan for modification of quality of life, with full involvement of the patient.
- (iii) Implementation of the actions identified to meet the specific needs.
- (iv) Evaluation of the outcome of the intervention and a review of the goals set.

Seen in this light it is hoped this concept of quality of life will stimulate further research into this difficult area.

Conclusions

An hypothesis concerning the nature of the quality of life has been proposed and some of its implications developed in a diagrammatic way. It is concluded:

- (i) The instruments developed to measure quality of life must take into account many aspects of life and life-style.
- (ii) The problems and priorities which are important are those of the individual and not of the observer.
- (iii) Measurement of quality of life is not sufficient in itself. Action should be taken to improve quality of life

(to narrow the gap) either by making expectations more realistic or by encouraging the individual to develop and grow in other ways.

- (iv) The emphasis should be on the positive aspects of narrowing this gap and improving quality of life.
- (v) Evaluation of any intervention to modify quality of life is essential.

It is useful perhaps to remember the words of Dr Samuel Johnson: 'I know not anything more pleasant, or more instructive than to compare experience with expectation or to register from time to time the difference between idea and reality'.

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- (10) McFarlane J, Casdoline G. *A guide to the practice of nursing using the nursing process*. London: C V Mosby, 1982.
- (11) Wood L L. *Medical records, medical education and patient care*. Cleveland, USA: Case Western Reserve University Press, 1969.

APPENDIX A

These are the general questions taken from "Questions the general public ask about cancer" by R L Davison. In the same paper there is a section showing the difference between the questions men ask and those women ask. The male ones are very much pre-occupied with smoking and lung cancer and the females ones with cervical cancer and smears.

- 1 Is cancer hereditary?
- 2 Is cancer on the increase?
- 3 Is cancer caused by knocks?
- 4 Does radiotherapy have unpleasant after effects?
- 5 Can cancer develop without symptoms?
- 6 Does cancer show up on an x-ray film?
- 7 Can cancer recur more than 5 years after treatment?
- 8 Does cancer occur in children?
- 9 Does smoking really cause cancer?
- 10 Is cancer always painful?
- 11 Are we born with it?
- 12 What about air pollution and lung cancer?
- 13 How long has it been there?
- 14 Is cancer infectious?
- 15 Is cancer caused by shock or worry?
- 16 Can doctors always recognise the symptoms?
- 17 Is weight loss a symptom of cancer?
- 18 Will they find a cure?
- 19 Aren't doctors responsible for delay?
- 20 Does surgery (or letting air get at it) hasten its development?
- 21 Why do some people get cancer and not others?
- 22 Should cancer patients be told the truth?
- 23 Can warts or moles become cancerous?

- 24 Is cancer more rapid in some than others?
- 25 Is radiotherapy painful and is it dangerous?

The questions patients most often ask me (WAFM) are:-

- 1 Will I die from it?
- 2 When will I die from it?
- 3 Will it hurt?
- 4 Will I need a bag or will I be disfigured?
- 5 Is it catching?
- 6 Does it run in families?
- 7 What did I do to make it happen?
- 8 What can I do to help myself?

What do radiotherapy patients want to know

- 1 What are the side effects of this treatment?
- 2 How long will I take to get over it?
- 3 Will I be alright or will I feel ill after the treatment?
- 4 Will I lose my hair?
- 5 Will I be sick?
- 6 How painful is the actual treatment going to be?
- 7 Will I feel anything?
- 8 How long will the treatment sessions last?
- 9 How long will I be in hospital?
- 10 How many treatments will I have to have?
- 11 How will I know whether the treatment is being successful?
- 12 Does this treatment work?
- 13 Will the treatment take the pain away?
- 14 What happens when I go for treatment?
- 15 Can I breathe when I am under the machine?

- 16 What is the machine like?
- 17 What are the do's and dont's?
- 18 Is this radium treatment?
- 19 How does the treatment work
- 20 If you have more treatments does that mean your condition is more serious?
- 21 Will the treatment make me radioactive?
- 22 Is is safe for my relatives to visit?
- 23 What are the radium badges for?
- 24 Why am I having x-ray treatment instead of surgery?
- 25 Is this treatment just for cancer?

These questions are taken from Anne Eardley's paper "What doe radiotherapy patients want to learn" Radiography 49: 122-124 (19823) as is the table:-

Table 3. Patients' fears on admission to the Christie, as reported by staff

	Percentage of staff who mentioned it
Fears relating to malignancy	51%
The name of 'Christie'-what it signifies	40%
Fear of the treatment	22%
Worry about after-effects	15%
Worry about the family	14%
Fear of the unknown	13%
Fear of dying in the Christie	11%
Fear of stigma	4%
Miscellaneous	4%

"The Christie" is Manchester's Regional Radiotherapy Centre (as Cookridge is for the Western half of the Leeds Region)

If you believe only a miracle can beat cancer, here's twenty.

To a lot of people the word 'cancer' is one of the most frightening in the English language.

They believe it's always incurable. That it's the death sentence by another name.

And that the only thing they can do about it is hope for a miracle.

For many cancer sufferers, however, there is already far more than just hope.

Below you'll find evidence of the progress cancer research has made in recent years.

Of the many thousands to whom the word 'cancer' is no longer a death sentence. And of the many areas of research now being successfully pursued.

Much remains to be done of course. (Especially since cancer does cause the death of nearly 142,000 people in this country every year.)

But as you'll see, cancer is being beaten.

1. As recently as 10 years ago, cancer killed hundreds of children every year. Now it's curable in 2 out of 3 cases.

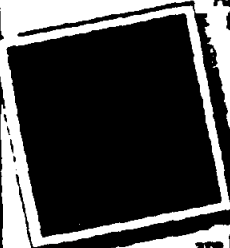
2. One in ten of all cancers are skin cancer. Most are now entirely curable.

3. Forty years ago, doctors had no drug treatment to give cancer patients. Today there are over 30 effective anti-cancer drugs.

4. In the 1950's only 1 in 3 children with Hodgkin's disease survived. Since then the success rate has doubled.

5. The discovery of links between cigarette smoking and lung cancer has done much to persuade people not to smoke.

And at last the deaths from lung cancer



Lorna Brancik was treated for cancer in 1971 and after three months was able to return to a full life.

are beginning to fall off.

6. Thirty years ago sufferers of testicular cancer had only a 50% survival rate. Today it's almost 90%.

7. The invention of the body scanner and its development during the 1970's has greatly improved the diagnosis and treatment of cancer.

8. Research has shown that 80% of cancers may be directly caused by our environment or life style, and therefore may be preventable.

9. Young people who would once have died from kidney cancer are now

usually able to make a full recovery.



10. The discovery of many cancer

Jenny Lockyer was treated for cancer 16 years ago. Today she leads an active normal life.

causing chemicals and materials, and the

subsequent controls placed on them has greatly reduced the chances of getting cancer at work.

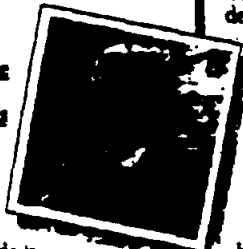
11. The introduction of cervical screening for women means that the risk of developing cancer of the cervix can be detected. And therefore, the disease is preventable.

12. Some hospitals now have specialist teams covering all aspects of cancer treatment, enabling patients to benefit from a greater range of expertise.

13. Not long ago 90% of all women with choriocarcinoma (cancer of the placenta) would have died. Today 90% recover.

14. Certain cancers of the ovary which occur in very young women were always fatal in the past. Now they are usually cured.

Eleven years ago John Hill was told he had cancer. Today he is cured and leads a full family life.



15. The discovery of certain antibodies which home in on tumours has made it possible not only to locate otherwise hidden cancers but also to target anti-cancer drugs to destroy them.

16. Developments in radiotherapy have produced more accurate and more powerful machines which make the treatment both more acceptable and more effective.

17. Just five years ago scientists could only theorize about the innermost workings of cancerous cells. Today, new technology is enabling them to unravel the whole mystery.

18. Research has discovered that cancerous tumours often produce marker-substances in the body. These can be detected at a very early stage when the cancerous tumours can be eradicated.

19. Not only are doctors and scientists finding ways to cure cancer they're also finding ways to ensure that the quality of life is subsequently undiminished.

20. In the past, cancer was almost inevitably a fatal disease. Today over 60,000 people are cured each year in Britain.

Of course, we at the Cancer Research Campaign cannot claim responsibility for all these developments.

They are the result of a worldwide campaign by many thousands of researchers and doctors.

Berry Mason was only eight when he developed cancer. Today he leads a normal schoolboy life.



However, as Britain's largest supporter of cancer research we do help finance over 600 projects throughout the country.

These cover everything from studying how cancer starts and how to prevent it, to developing new techniques for early detection and cure.

To continue these projects and start more, we need your contribution. This can be either a donation through a deed of covenant, legacy or money.

Or a donation of your time in helping our local committees.

Over 92% of all the money we collect goes straight into research.

So however you can help us, you can be sure you'll be helping to give Britain's cancer sufferers a better chance.

Write to us now at Dept. G1, 2 Carlton House Terrace, London SW1Y 5AR.

Or contact your local Cancer Research Campaign through the telephone directory.

The sooner you do, the sooner we'll be able to add another miracle.

Together, we can beat cancer.

Thomas 'the tank engine' Parker

APPENDIX C

Support of the Cancer Patient by reference to various agencies

- 1 BACUP (The British Association of Cancer United Patients) founded in late 1985 by Dr Vicky Clement Jones, who herself suffered from advanced cancer at the time. BACUP produces a large number of excellent booklets on different aspects of cancer. They cost money but are free to patients and relatives or main supporters. More information is available from BACUP, 121/123 Charterhouse Street, London EC1N 6AA,
Tel No 01 608 1785 (Administration)
01 608 1661 (Cancer Information Service)
and now on Freephone anywhere in England
Tel No 0800 181199

- 2 Tak Tet) This Cancer Support Group
Tak Tent Office) Organisation
4th Floor) in Scotland is the best I know.
G Block) A model for all Cancer Support
Western Infirmary) Groups.
Glasgow)

Tel No 041 3574519
Tel No answering machine 041 3346699

- 3 The National Cancer Institute of America publish a large amount of reading material for doctors and patients about various aspects of cancer and their address is:-
The Office of Cancer Communications
National Cancer Institute
Building 31, Room 10A 18
Bethesda
Maryland 20892

All this material is available to you if you merely write to them introducing yourself and saying what you want.

Appendix D is a photostat of the order page in the publications list in May 1990. This publication list is updated every four months.

- 4 Cancerlink is a National Organisation which runs a directory of cancer support groups. Its address is:-
17 Britannia Street
London
WC1X 9JN

or

9 Castle Terrace
Edinburgh
EH1 2DP

This whole field of support of the cancer patient by non medical sources is growing fast and needs to be taken into account, because many of the agencies are very helpful

Locally in Yorkshire

Airedale Cancer Support Group
Airedale General Hospital
Steeton
Keighley
Tel No 05353 655207

Bradford Cancer Support Centre
2nd Floor
72 Vicar Lane
Bradford
West Yorkshire

Hebden Bridge Cancer Support Group
Hob Cote
Midge Hole
Hebden Bridge
HX7 7AH
Nerissa Waring: 0422 842739

North Humberside Cancer Support
Janice Ness
Dove House
Beverley High Road
Hull
HU6 7NH
0482 448862

Bridlington & District Breast Cancer Help
24 South Back Lane
Bridlington
North Yorkshire
YO16 4EX

R.V Club (Radical Vulvectomy)
10 Croft Street
Upton
Pontefract
Tel No 0977 640243

Ryedale Cancer Support Group
16 Ryedale Close
Norton-on-Derwent
Malton
North Yorkshire
YO17 9DQ
0653 600211

Scarborough Cancer Support Group
Arch View
Roxby Road
Thornton Dale
Pickering
North Yorkshire
YO18 7SX
Daytime number:
George Bennett 0751 73138
Evening number:
Janet Johnson 0723 364755

Scunthorpe Cancer Support Group
41 Frances Street
Scunthorpe
Humberside
0727 845155 (office hours)

Selby and District Cancer Aftercare
45 Ash Grove
Ricall
North Yorkshire
YO8 9PP
Andrea Walker: 0757 248970

Yorkshire Cancer Help Centre
1 West End Avenue
Harrogate
North Yorkshire
HG2 9BX
Esme Patterson: 0423 521637
Answer machine: 0423 501527

65
ORDER FORM: PUBLICATIONS LIST FOR THE PUBLIC AND PATIENTS

Please fill out order form and indicate quantity required

Appendix D

CANCER PREVENTION MATERIALS (Limit 200)

- _____ Chew or Snuff is Real Bad Stuff
- _____ Clearing the Air: A Guide to Quitting Smoking
- _____ Diet, Nutrition & Cancer Prevention: The Good News
- _____ Everything Doesn't Cause Cancer
- _____ Good News, Better News, Best News...Cancer Prevention
- _____ Good News for Blacks About Cancer
- _____ Why Do You Smoke?

EARLY DETECTION MATERIALS (Limit 200)

- _____ Breast Exams: What You Should Know
- _____ Questions & Answers About Breast Lumps
- _____ Smart Advice for Women 40 and Over: Have a Mammogram
- _____ Testicular Self-examination

GENERAL MATERIALS (Limit 100)

- _____ Asbestos Exposure: What It Means, What To Do
- _____ Cancer Facts for People Over 50
- _____ Cancer Information Service Leaflet (1-800-4-CANCER)
- _____ Did You as a Child or a Young Adult Have X-ray Treatments Involving Your Head or Neck?
- _____ Research Report (Series)
 - _____ Adult Kidney Cancer and Wilms' Tumor
 - _____ Bone Marrow Transplantation
 - _____ Cancer of the Bladder
 - _____ Cancer of the Colon and Rectum
 - _____ Cancer of the Lung
 - _____ Cancer of the Ovary
 - _____ Cancer of the Pancreas
 - _____ Cancer of the Prostate
 - _____ Cancer of the Stomach
 - _____ Cancer of the Uterus
 - _____ Hodgkin's Disease & the Non-Hodgkin's Lymphomas
 - _____ Leukemia
 - _____ Melanoma
 - _____ Mesothelioma
 - _____ Nonmelanoma Skin Cancers: Basal and Squamous Cell Carcinomas
 - _____ Oral Cancers
 - _____ Soft Tissue Sarcomas in Adults and Children
 - _____ Testicular Cancer
- _____ Understanding the Immune System
- _____ What You Need to Know About Cancer...(Series)

<ul style="list-style-type: none"> _____ Cancer _____ Bladder _____ Bone _____ Brain and Spinal Cord _____ Breast _____ Cervix _____ Colon and Rectum _____ Esophagus _____ Hodgkin's Disease _____ Kidney _____ Larynx _____ Adult Leukemia _____ Childhood Leukemia 	<ul style="list-style-type: none"> _____ Lung _____ Melanoma _____ Multiple Myeloma _____ Non-Hodgkin's Lymphoma _____ Oral _____ Ovary _____ Pancreas _____ Prostate _____ Skin _____ Stomach _____ Testis _____ Uterus
--	--

PATIENT MATERIALS (Limit 100)

- _____ Advanced Cancer: Living Each Day
- _____ Breast Cancer Patient Education Series
- _____ Breast Biopsy: What You Should Know
- _____ Breast Cancer: Understanding Treatment Options
- _____ Mastectomy: A Treatment for Breast Cancer
- _____ Radiation Therapy: A Treatment for Early Stage Breast Cancer
- _____ Adjuvant Therapy: Facts for Women with Breast Cancer
- _____ After Breast Cancer: A Guide to Followup Care
- _____ Breast Reconstruction: A Matter of Choice
- _____ Cancer Treatments: Consider the Possibilities Chemotherapy and You
- _____ Diet and Nutrition: A Resource for Parents of Children with Cancer
- _____ Eating Hints
- _____ Help Yourself: Tips for Teenagers with Cancer
- _____ Hospital Days, Treatment Ways
- _____ Managing Interleukin-2 Therapy
- _____ Radiation Therapy and You
- _____ Taking Time: Support for People with Cancer and the People Who Care About Them
- _____ Talking With Your Child About Cancer
- _____ What Are Clinical Trials All About?
- _____ When Cancer Recurs: Meeting the Challenge Again
- _____ When Someone In Your Family Has Cancer
- _____ Young People With Cancer

SPANISH LANGUAGE GENERAL MATERIALS (Limit 200)

- _____ A Time of Change: De Niña A Mujer
- _____ Guia Para Dejar De Fumar
- _____ Buenas Noticias, Mejores Noticias, las Mejores Noticias... Prevencion del Cancer
- _____ La Prueba Pap
- _____ Lo Que Usted Debe Saber Sobre el Cancer

SPANISH LANGUAGE PATIENT MATERIALS

- _____ Facts on Cancer Sites (Limit 1)
 - _____ Colon y del Recto (Colon and Rectum)
 - _____ Displasia (Dysplasia)
 - _____ Pulmon (Lung)
 - _____ Boca (Mouth)
 - _____ Prostata (Prostate)
 - _____ Estomago (Stomach)
 - _____ Utero (Uterus)
- _____ El Tratamiento De Quimioterapia Para El Cancer (Limit 100)
- _____ La Radioterapia Para El Cancer (Limit 100)
- _____ Anticancer Drug Sheets in Spanish-English (Limit 3)

ALLOW 4 TO 6 WEEKS FOR DELIVERY OF LARGE ORDERS

Please mail this form to: Publications Order
Office of Cancer Communications
National Cancer Institute
Building 31, Room 10A 24
Bethesda, Maryland 20892

Or Call:
1-800-4-CANCER

5/90

Name (print or type)

Organization

Street and Number

City State Zip Code

APPENDIX E

Other sources and references

1 The Oncology Information Service of YRCO

Address: Medical & Dental Library
 University of Leeds
 LEEDS
 LS2 9JT

Publishes a monthly list of references on cancer topics classified by systems of breast, digestive system, drug therapy, pain etc, which is comprehensive and valuable.

2 Talking to Patients with Cancer and their families

Raymond N Lowenthal
 Cancer Care volume 3 Issue 3, July 1986 page 5-10

This is an extremely practical and useful paper on which you can base your practice. Its "key principles" are as follows:

- a) choose placid surroundings
- b) encourage participation of close family and friends
- c) be honest and positive
- d) never deny hope
- e) allow airing of myths and correct them
- f) give an honest, yet imprecise prognosis - emphasise the variability of cancer
- g) anticipate interest in alternative treatments
- h) communicate with other members of the treatment team
- i) encourage a 2nd opinion if warranted
- j) be available
- k) listen

The rest of this article is also extremely valuable.

3 Understanding the Cancer Patient: The Caregivers Plight

A D Weisman, Psychiatry 44 page 161-168 (1981)
 "there is no reaction among patients that cannot also occur in care givers"
 (This one was found for me by a final year student in 1986)

4 The Psychosocial Dimensions of Cancer

Richard Goldberg & Robert M Tull, The Free Press
 N Y (1983)

This is what it says: A practical guide for health care providers.

It has an excellent Appendix A: semistructured interview for parent and spouse with lots of questions we should be asking.

- 5 **Consultation skills of young doctors**
Peter Maguire, Susan Fairburn, Charles Fletcher
BMJ volume 292 June 14th 1986 page 1573-1578

There are two short papers here. They show how poor we are at giving bad news and how much training is necessary to improve our performance. Every medical student and every teacher should know about this and we should all do something to try to help the situation.

- 6 **Philosophical Medical Ethics** - a very high-brow series in the BMJ 185-6 deals with lots of thorny philisophical problems.

- 7 **Which way to Health - The Journal of the College of Health**

The College of Health was established in 1984. It is run along the lines of the Which Magazine, by the same editorial board, and it is a vital source of information about what patients are thinking and also what they are led to think by the writers in this useful magazine and the press at large.

It is well worth a subscription and it is published every month by the Consumers Association

PO Box 44
Hertford
SG14 1SH

- 8 **Self help groups: the fourth estate in medicine?**
Stephen Lock
British Medical Journal 293 1986 page 1596-1600

A fine review of the formation and function of self help groups in general. I would make a distinction and suggest

a self help group is what it says it is and a support group has professional input of guidance and advice. Many of the best "self help" groups have an important professional backup as described in this article.

- 9 **I don't know what to say - Dr Rob Buckman Papermac 1988**

This book is designed to help support someone who is dying.

It is also a great help for anyone handling the giving of bad news and is easy to read. Highly recommended.

10 MITA



The Medical Interview Teaching Association

If you become involved in teaching then this small dedicated group is a very valuable resource for someone interested in doctor/patient communication skills. The person to contact is:-

Dr Julian Bird
25 Montpelier Row
Blackheath
LONDON
SE3 0RT

Tel No: 081 852 0157

Dr Julian Bird, Chairman of MITA, compiled a report Teaching Doctor/Patient Communication Skills. If you wish a copy of it or want to discuss the topic with him please contact him at the above address.

APPENDIX F

Information I like to know about cancer patients I am treating

Every history taking session seems to be different. There are a few questions which come up over and over again and they are worth emphasising. I will try to deal with them in the order in which I usually try to ask them, but when I take a history I try to be very flexible and jump from one question to another, if the opportunity arises, rather than grind through a preconceived list in the order in which I can remember it. Therefore, although these questions are in order in which I would like to tackle them, I often tackle them in a different order in any particular interview:-

- 1 What do you (the patient) know, about what you have got, what diagnosis has been given to you and by whom?

With this question I want to define where the patient stands and what knowledge he or she thinks they have before we start.

This is the most important question in any interview with any patient. Whatever the patient has been told before and whoever told them, (even if I have told them myself), I still like to ask them where they think they have got and what they think they know so that I can build on the patient's own perception of his or her situation, rather than any preconceived idea I might have about what has been told. I therefore find it very difficult to be happy about the idea that one can pass on communication in this area by notes in a case sheet. There are many ways of noting the interview. The best I know is to record in the briefest possible terms in the notes; the key question(s) of the interview - eg

Q (the patients question) "Have I got cancer?"

A (my answer) "Yes it is a form of cancer of the stomach and you will need an operation".

I try always to use the word "cancer" so that we can talk about it freely, the patient and I, and I can use the exchange as an educational exercise indicating my views on the particular cancer which affects the patients. This means that we do not talk about cancer in general terms but cancer as it applies to the patient, but we use the general word because everybody seems to understand that word more or less.

The other questions I like to ask are:

- 2 Who else has talked to you. (Was it a doctor, relatives, friends or anybody else?)

- 3 What previous experience of cancer have you had, if any?
Tell me about if it you have?

This is a most useful question because if that patient has had a previous experience of a similar cancer than a lot of the questions and answers that usually crop up have already been answered and the interview goes very much more smoothly.

- 4 What sort of person are you? Fighter? Denier?
Passive? Active? Previous psychiatric illness?
Religions?

- 5 What do you think/know about cancer?

This one allows me to correct negative views, if correction is appropriate, explain old wives tales and generally help the patient with up to date accurate medical knowledge and information, coloured by my own opinion of the management of this particular patient's problems.

- 6 Are you a reader who will search out answers in newspapers, magazines, books?

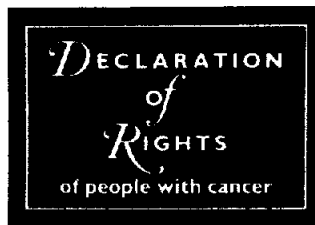
This is useful because if the patient is a reader you can help him or her, by providing accurate up to date modern information about their disease or the The Power of Positive Thinking, see page 14. It is equally helpful if the patient is not a reader because if not he or she is usually a strong denier, and one can encourage the strong denial since that is a powerful way of dealing with problems.

- 7 Are you a religious person? If not where will you look for psychological or spiritual strength?

- 8 What do you feel about alternative methods of management of cancer?

This one allows me to find out if she wants to rush into cranky diets or if he is reasonably likely to be satisfied with the NHS, as he finds it.

There are lots of other questions to ask but these 8 are quite definitely the core of information which I use in my daily practice with cancer patients. Other ideas you can get from books and if they seem to be good, then you must make use of them. If you take an interest in this rich and interesting area of life, you will be good at managing patients with all sorts of chronic problems, such as diabetes, rheumatoid arthritis, multiple sclerosis etc as well as those with cancer.



This Declaration of Rights of People with Cancer has been produced by CancerLink to bring the needs of people with cancer to the attention of health professionals, employers and the public at large.

The document is designed to act as a starting point for debate about how the needs of people with cancer are being met and how service provision could be improved.

The following do not all exist as legal rights but are felt to be fundamental to the well being of people with cancer.

I have the right:

1. ... to equal concern and attention whatever my gender, race, class, culture, religious belief, age, sexuality, lifestyle, or degree of able-bodiedness.
2. ... to be considered with respect and dignity, and to have my physical, emotional, spiritual, social and psychological needs taken seriously and responded to throughout my life, whatever my prognosis.
3. ... to know I have cancer, to be told in a sensitive manner and to share in all decision-making about my treatment and care in honest and informative discussions with relevant specialists and other health professionals.
4. ... to be informed fully about treatment options and to have explained to me the benefits, side effects and risks of any treatment.
5. ... to be asked for my informed consent before I am entered into any clinical trial.
6. ... to a second opinion, to refuse treatment or to use complementary therapies without prejudice to continued medical support.
7. ... to have any special welfare needs acknowledged and benefit claims responded to promptly.
8. ... to be employed, promoted or accepted on return to work according to my abilities and experience and not according to assumptions about my disease and its progression.
9. ... to easy access to information about local and national services, cancer support and self help groups and practitioners that may be useful in meeting my needs.
10. ... to receive support and information to help me understand and come to terms with my disease, and to receive similar support for my family and friends.

