**PATIENT INFORMATION PROVISION: ITS EFFECT ON PATIENT ANXIETY
AND THE ROLE OF HEALTH INFORMATION SERVICES & LIBRARIES**

by

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A B S T R A C T

The history of patient information provision is a chequered one and can be traced as far back as Hippocrates. It is once again becoming prevalent and being attributed some importance. Health promotion and education is gradually allowing consumers to be more in control of their own health care. This dissertation is concerned with the importance of communicating information to patients as an aid to recovery by decreasing anxiety. Recent research suggests that pre-operative information helps to decrease post-operative stress and leads to a quicker recovery. A research project, the Acorn Project, is currently testing out this belief. Written information has become an important supplement to oral communication and is seen as being effective as long as it is easily understandable and cannot be misinterpreted.

The health belief model has proven to be an effective predictor of individuals' responses towards health-related matters. It is described as a useful theoretical framework for medical professionals in deciding the content and quantity of information that each patient should receive. A number of anxiety measures are described and a study for further research is suggested, exploring the hypothesis that reading about illness significantly helps to reduce anxiety when the patient has added emotional support from a health professional.

The existing problem of who is ultimately responsible for giving information to patients is highlighted in the general practice, hospital and public settings. Recommendations are made for the improvement of patient information provision in these three areas. Librarians are seen as being in a good position to liaise with medical professionals to provide the most effective health information service possible for patients and the consumer in general. Many changes are required before such co-operation can be achieved.

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DEDICATION

To Ian

for your safe and happy return from Kenya

With all my Love

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CHAPTER ONE

INTRODUCTION

Health and health care provision are extremely important parts of everyone's lives. Good health goes together with well-being, happiness and the freedom to do endless things in life. The proverb 'health is better than wealth' certainly embodies the value good health has in the quality of life.

The recent trend towards health education and promotion, which is beginning to take root in this country, is encouraging the consumer to concentrate on maintaining good health. The emphasis now is on attaining and maintaining good health through changes in lifestyle, rather than just eliminating disease, which can only be good for the health of Britain in the long term.

As Sally Knight, Health Information Librarian at Lister Hospital in Stevenage, says:

Although health is something which concerns everyone, until quite recently, the matter of consumer education has been seen as an unnecessary burden. Paternalism has played a part in this field to an extent rare in others ... The situation illustrates the degree to which the medical profession has guarded its preserve (1).

The provision of consumer health information and patient information is a necessary part of the educating process. Medical professionals are renowned for their inability to communicate effectively with their patients and, until

recent times, the consumer has accepted a more passive role in health care. These days, however, the consumer is demanding more as the message of self-care is beginning to take hold.

It has been said that seeking medical information:

... may not only enhance his [the patient's] capacity for independent health problem-solving in regard to a particular symptom or illness but for lasting independent functioning in general (2).

The main focus of this dissertation, in line with today's health climate, is patient information provision, its effects on patient anxiety and the consequent effect on the role of health information services and libraries.

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CHAPTER TWO

HISTORY OF GIVING INFORMATION TO PATIENTS

Judging from the vast array of health information sources which are available today, it seems hard to believe that less than half a century ago many of those in the medical profession may have laughed, or even been horrified, at the idea of giving information to patients, not only as an aid to recovery, which is a relatively new idea, but also as the patient's right to know about their own state of health.

Now, information can be found everywhere, ranging from leaflets in GPs' surgeries, magazines and even television advertisements, to a number of health information services which are mushrooming all over the country. This pattern indeed reflects the growth pattern of consumerism, defined by the *Oxford English Dictionary* as, 'the protection of purchasers' interests', which took root in the 1960s, and which can only be described as flourishing in the 1990s. Robert Gann describes the first half of this century as:

a period of scientific and technological change in Western medicine, which served to enhance the power and mystique of doctors (1).

He continues to pinpoint the 1960s as a period when there was:

a growing realisation that further improvements in health may be beyond the reach of medicine, and depend rather on changes in individual and community behaviour (2).

Hence, the emphasis is now on health promotion and information.

THE TWENTIETH CENTURY

The idea that such an emphasis has not always been a priority is true. To a certain extent and, in particular, during the first half of the 20th century, the image of the doctor as completely competent and in control, with the patient as purely co-operative and passive, was prevalent. Talcott Parsons (1951) believed in a 'competence gap' which:

... ultimately justifies the physicians social position as legitimate authority and professional, as well as the patient's obligation to trust in and comply with the physician's clinical prescription (3).

Hence, the patient assumes a 'sick role' who, wishing to become well again, places all and unquestioning confidence in the doctor who will be expected to prescribe and be obeyed.

In this rather harsh doctor-patient scenario, Talcott Parsons believes that the doctor, as a professional, may assume social superiority over the patient, and it is this that gives him or her ultimate authority. This is an interesting concept which serves to highlight the lack of patient perspective in the theory and which contrasts greatly with slightly later theories and the whole idea of consumerism, which is so strong today. Eliot Freidson (1970) is one theorist to oppose the rigidity of Parson's view. He recognises that:

... for many patients the authority of the physician is far from absolute. For example, the patient's degree of education or the support he or she receives from family and friends may indirectly affect the information exchange

between physician and patient (4).

Here can be seen the total upturning of Parson's view that the patient's social environment can greatly affect the doctor-patient relationship, and that the doctor's social superiority through his professional status cannot be assumed as the basis for any consequent communication or consultation.

THE CENTURIES BEFORE

To concentrate on the 20th century alone would however, do a grave injustice to the whole history of giving information to patients because, as Gann states, 'interest in the topic goes back for many centuries'(5). He quotes Hippocrates, who, 2,000 years ago, wrote:

In the art of medicine, there are three factors - the disease, the patient and the doctor. The doctor is the servant of the art. The patient must co-operate in fighting the disease (6).

It is heartening to read that the patient is seen as having an active role in the doctor-patient relationship all those centuries ago. It is, though, rather ironic that Hippocrates should damn his own philosophy by advising physicians to:

... perform duties calmly and adroitly, concealing most things from the patient (7).

The same confusions in doctor-patient relationships can be

seen to have existed 2,000 years ago, and are, to some extent, still in existence today.

Gann continues to explain in his article that in the seventeenth century:

the physician would be consulted only for the most alarming or disabling conditions. A more natural course would be to seek the advice of family, friends and neighbours (8).

This is especially interesting to note as the idea of self-care, with an emphasis on prevention of illness and disease, has become such a key issue in contemporary times.

The nineteenth century saw an emphasis on:

... the diffusion of sound information in a popular and readable form fitted to make the people sensible of their responsibility and to use all means in their power to preserve their own health and the health of those dependent upon them (9).

Again, the apparent emphasis on the importance of self-care is quite marked, particularly, 'the attention to readability and accessibility of information'. The concept of having accessible health information for the consumer as well as for the medical professions seems such a recent trend that it is quite startling and humbling to see such reflections in the history of our own country.

The second half of the twentieth century is therefore experiencing a re-emergence of the role of the patient as an active participant in medical care.

Indeed, the average level of education has steadily risen in Western society over the last

few decades and the public is better informed now than ever before about health matters (10).

RECENT DEVELOPMENTS AND RESEARCH

The idea of consumers taking responsibility for their own health care by seeking out available information is now being taken a forward step. The belief is that giving information to patients actually aids recovery by reducing the anxiety levels experienced by patients during illness, treatment and recuperation. DiMatteo and DiNicola state:

There is, without doubt, an intimate relationship between anxiety and information but the precise character of that relationship cannot yet be specified. It is critical to understand this relationship in attempting to clarify and enhance practitioner-patient communication in medical care (11).

Theories suggest that information helps to reduce anxiety, thus allowing the patient to have perceived control over the illness or treatment which, in turn, helps the patient to have a more positive attitude towards his or her own particular health situation. The fact that this may help to reduce physical symptoms and recovery rates is, as yet, an unexplained wonder, and one which not all doctors seem willing to take on board. A *Guardian* article from 1989 reported on a claim made by *Which?* magazine:

Patients' rights are being trampled underfoot because doctors have neither the time nor the inclination to explain medical and surgical treatments to them (12).

A spokesman for the magazine is quoted as saying:

Some doctors argue that detailed information is time-consuming, could frighten patients unnecessarily and that there's no guarantee that patients will understand what they are told... However, people aren't as interested in technical details as in implications - what an operation will mean for them personally (13).

This argument highlights the confusion over how much information should be given to the patient and exactly what kind of information is the most beneficial in any given situation. The fact that this may depend on the individual concerned, and should not be swept under the carpet by members of the medical profession, as the *Which?* article implies is happening, shall be discussed in more detail in a following chapter.

PATIENT PARTICIPATION

There is a considerable amount of research, however, which has shown that:

increasing a patient's participation in his or her own care can lead to improved disease control, a better quality of life, and a more satisfactory relationship with the physician (14).

Such a trend may have started with the treatment of illnesses such as diabetes, where medication is required every day for those suffering with the disorder. The most effective way of administering such treatment is to teach the patient how to take the medication himself, allowing him to take control of his care and alleviating the doctor of a large responsibility. If a young child, diagnosed as having diabetes, is not only taught by the doctor the every-day procedures which have to be undertaken, but also

has explained why they have to be done, then complete compliance to the recommended treatment is likely to be achieved. He or she will then be able to achieve effective self-care for the rest of their life, and will only need to be treated by the doctor for more complicated problems associated with the illness - a bonus in today's difficult economic climate.

In their study, Brody et al attempted to compare the differences between what they call 'active' and 'passive' patients who visited a general practice.

Active patients can be described as those who go to their GP wishing to gain information so that they can feel in control of their own situation. The results show that not only do 'active' patients feel more satisfied with their doctor after consultation but were also 'more than twice as likely to feel that their illnesses had improved maximally one week after the visit compared with patients who felt they had played more passive roles (15).

Hence, the article concludes, patients who feel they have actively participated in their own health care experience more positive results than those who believe they have taken a more passive role. It is only fair to point out, however, that this can only relate to those who are capable of taking an active role, as a patient who is seriously ill may wish to take a more active role than is physically possible.

PATIENTS' PERCEPTION OF HEALTH CARE

It is interesting that Brody et al emphasise the patient's perception of his or her own health care. A similar article by Lerman et al highlights the same idea:

In our study, changes in patients' attitudes about their illnesses, such as their understanding of their medical problems, their concerns, and their expectations for improvement in functioning, were related to their perceptions of physicians' efforts to encourage involvement, as well as to the levels of information exchange (16).

What the study actually shows is that patients do not necessarily wish to take part in the technical decision-making of what to do about their problem as, after all, this is what the doctor is qualified to do. They wish to feel that the doctor has listened and taken account of their points of view, worries and concerns. It is the patient's perception of this which is all important in their consequent satisfaction of their medical care in general and which may help their ultimate recovery rate and health outcomes.

Research clearly shows that what patients want is a form of compassionate medical care, which includes a good, satisfactory doctor-patient relationship as well as information about their condition. Many of the issues related to health care depend very much on the doctor-patient relationship, and as it is such a complex topic, it is discussed in more detail in Chapter 6.

THE NURSING LITERATURE

With such a current emphasis on the provision of information to patients and the emergence of Project 2000, the nursing profession has been just as affected, if not more so than the doctors themselves, by the consumerist movement. The nursing literature certainly seems to reflect this:

... the profession must confront the issue that client participation really means handing power back to the client ... both clients and nurses alike must reassess the common expectations associated with their roles if clients are to achieve healthier life-styles and nurses are to be successful as health educators (17).

Nurses are therefore being seen as having a very major role in health promotion and education, with the Royal College of Nursing itself describing it as 'one of the main routes to professional excellence' (18).

Laura Swaffield reassesses the common expectations associated with the roles of patient and nurse, in an article which challenges the traditional idea of health-educator as infallible. She envisages a more flexible programme which is geared towards the individual, hence giving the patient more power over his or her own health programme, decisions, thoughts and ways of recovery. She believes that '... even more important than the questions you ask is the way you listen to the patient' (19). The emphasis on listening serves to enhance the results found by Lerman et al in their article mentioned earlier. Swaffield concludes:

The god-like, all-knowing health educator is a hard role to keep up. The listening, fallible health educator could well be a less stressful approach, and the evidence shows it is almost certain to be a more successful one (20).

The nursing profession certainly seems to be in tune with the most recent thinking on the subject of giving information to patients, which reflects the sentiments implicit in the recent research findings on patient

participation and the benefits of information in health care. It may be, however, that Project 2000 is forcing the nursing profession to be more aware of this subject as they gradually gain extra responsibilities in the area of the health education of patients - a role which will be discussed further in connection with health promotion in Chapter 3.

SUMMARY

The seemingly new idea of giving information to patients can, in fact, be traced back for many centuries. Although many studies have been undertaken to test the effect that providing information has on patients, there is still more research needed to decipher exactly how much and what kind of information is required. The patients need to perceive that they have received the best treatment possible so that they can be fully satisfied with the health care provided. Fortunately the ideas, especially in the nursing profession, are beginning to take shape.

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CHAPTER THREE

THE RISE OF HEALTH PROMOTION

The current emphasis on consumer health information, in an attempt to prevent disease and increase self-care, has brought with it the concept of health promotion as a 'new way of encouraging health in the community' (1).

In 1984, the World Health Organisation published a document, 'Health for All', which set a total of 38 targets for all European countries to achieve by the year 2000. The targets range from reducing the inequalities in health between social groups, improving the environment and housing, developing policies to aid healthy lifestyles (2) to the development of a:

broad and dynamic health literature service in order to make health materials available to as many users as possible (3).

THE HEALTH EDUCATION AUTHORITY

The first signs that the British government had taken any notice of WHO's recommendations appeared in 1987, when the Health Education Council was abolished and replaced by the Health Education Authority. As a measure largely to help in the prevention of the spread of AIDS, it was also a big step towards creating a national focus for the promotion of health information in general, especially since it is part of the NHS, an official status not enjoyed by the previous council (4).

'WORKING FOR PATIENTS'

It was not until 1989, however, that the first big shake-up in the NHS occurred, with the emergence of the government's White Paper, 'Working for Patients'. Its introduction:

stipulated that a new era of patient care be introduced, the focus shifting from medical care and treatment to health education, health promotion and health information (5).

The restructuring should theoretically leave the district health authorities time to concentrate on strategic planning to shift this focus, although in reality the changes may cause so much confusion that valuable time is spent trying to sort administrative and procedural matters.

The White Paper also includes an aim to create:

'... effective services for the prevention and control of diseases and the promotion of health

and one way of achieving this is via community medicine and community health:

The Department of Health ... required health authorities to ensure that full use is made of family planning services as a resource in combatting AIDS and in their wider health role, e.g. in cervical smear testing. As an anonymous self-referring community based service working in the field of sexuality, family planning services are well placed to give information and provide other services to prevent the spread of HIV (7).

It seems, therefore, that family planning clinics are considered to be one of the most important health services in the community as a whole. What is so ironic is that, given such a rated position in the community, their funding has been reduced drastically over the last few years. Harriet Harman, the Shadow Minister for Health, has stated:

family planning is a vital, preventive health care service for women ... But cash-starved health authorities, anxious to keep hospitals and wards open, are picking on family planning services as a 'soft option' for cuts (8).

If family planning clinics are so vital to the government's health promotion programme in helping the prevention of AIDS and the spread of the HIV virus, then definite guidelines for their budgets should have been made clear in the White Paper.

Another threat to the services came in April, 1990, with the introduction of the new GP contract. GPs are now being given large financial incentives to carry out smear tests and immunisation programmes for young children which places them in direct competition with the family planning clinics. Therefore, unless plans are made to harmonise the two and unless family planning services gain more financial backing, the government's stated important role for them will fail.

WHAT IS HEALTH PROMOTION?

Health promotion emerged as a concept in the late 1970s in North America. The US Department of Education, Health and Welfare has explained:

... it begins with people who are basically healthy and seeks the development of community and individual measures which can help them to develop lifestyles that can maintain and enhance their state of well-being (9).

Another definition has been attempted by Peter Draper, from the Department of Community Health at Guy's Hospital in London. He describes health promotion as:

... both health education and all attempts to produce environmental and legislative change conducive to good public health. Health promotion is concerned with making healthier choices easier choices (10).

It can be seen from these definitions that, although individuals in the community are given the responsibility for maintaining their own health wherever possible, they need legislative support from the government to enable them to do so. Over recent years, it has been the Conservative Government policy to place complete responsibility on the individual, whilst seemingly ignoring their social environment and financial circumstances. These are often factors outside the individual's control which can indirectly affect lifestyles and consequently their health. The Black Report, as far back as 1980, recognised that:

although the health of the less well-off could improve with better and more appropriate antenatal care and preventive services, such as cervical screening, much of the difference was down to poverty, work conditions, housing and environmental deprivation (11).

THE BLACK REPORT

The Black Report is the published results of a Working Group on Inequalities in Health which, in the words of Patrick Jenkin, the Secretary of State for Social Services, was set up in 1977 to:

review information about differences in health status between the social classes; to consider possible causes and implications for policy, and to suggest further research (12).

This review was as a consequence of the Conservative government's recognition that Britain was lagging behind some other countries in their overall health improvement, due mainly to the large differences in health between the varying social classes.

Much controversy surrounded the report as its findings were not only dismissed by the government as being far too inconclusive and expensive to carry out but very few copies were actually printed and circulated, hence arousing much publicity and criticism at the time. The Working Group argued that:

... much of the problem lies outside the scope of the NHS. Social and economic factors like income, work (or lack of it), environment, education, housing, transport and what are today called 'life-styles', all affect health and all favour the better-off. Yet they have largely remained outside the ambit of national health policy (13).

As a result of their findings, the Black Report, so called because it was chaired by Sir Douglas Black, President of the Royal College of Physicians, formerly Chief Scientist

at the Department of Health, made 37 recommendations. These include:

... giving effect to improvements in information, research and organisation so that better plans might be drawn up, redressing the balance of the health care system so that more emphasis is given to prevention, primary care and community health ...

and

... radically improving the material conditions of life of poorer groups, especially children and people with disabilities (14).

Patrick Jenkin's response to the Report in 1980 is revealing, especially in the light of recent political developments which shall be discussed further in the chapter:

I must make it clear that additional expenditure on the scale which could result from the report's recommendations - the amount involved could be upwards of £2 billion a year - is quite unrealistic in present or any foreseeable economic circumstances, quite apart from any judgement that may be formed of the effectiveness of such expenditure in dealing with the problems identified. I cannot, therefore, endorse the Group's recommendations (15).

This was stated even after the Report suggested that although it realised more money would need to be ploughed into the social services, not all its recommendations would be too expensive and those that were could be phased into legislation gradually so that the government would not have to pay for the costs all at once.

The Working group was therefore convinced that:

... it is difficult to begin to explain the pattern of inequalities except by invoking material deprivation as a key concept (16)

thus refuting the words of many ministers. These include the former Junior Minister for Health, Edwina Currie, and Ann Widdecombe, Social Security Minister, who have persistently:

... continued to favour the argument that health differences are due to individual patterns of behaviour, despite the evidence to the contrary. In other words, they are blaming the victims, not their circumstances (17).

Another criticism in Deborah Cohen's article is the lack of co-operation between the different government departments on matters of health. If the government is to set a precedent to the rest of the country on healthy eating and healthy lifestyles, then all ministries should be in line with the policies. The Department of Health, for example, tells us to improve our diets by eating less fatty food when the Department of Agriculture is positively encouraging the growth, for financial reasons, of fatty meats. There is a similar problem over tobacco and alcohol, which also create a large revenue for the government. The Coronary Prevention Group has been campaigning for just such co-operation between the different government departments.

'THE HEALTH OF THE NATION'

At the time of publication of Deborah Cohen's article in

1989, there had been no action from the government to implement concrete national strategies towards health promotion, as recommended by the WHO and the Black Report, and this has remained the case until June, 1991, seven years after the WHO's document was released, and eleven years after the publication of the Black Report.

On 4 June, 1991, the government released a Green Paper entitled 'The Health of the Nation', after much criticism that England is lagging far behind other European and world countries in its preventive health planning. The *Guardian* rather ironically states:

Judged by what has gone before, yesterday's document from William Waldegrave [Health Secretary] signals social revolution. It recognises the need to stop concentrating purely on the country's sickness service and to turn to preventive health measures as well (18).

The Paper has been described as containing:

Ambitious targets to reduce death and illness from heart disease and strokes in people under 65, to reduce smoking, increase exercise and cut fat consumption ... (19).

It calls for radical changes to people's lifestyles to help prevent cancer, as well as heart disease and strokes. The main factors signalled out as being major contributors to ill-health are smoking, diet and alcohol and they are calling for improvement in the areas of child health and in areas of potential harm, such as AIDS and other communicable diseases.

The Black Report's findings, eleven years ago, that ill health is linked to poverty has been finally accepted by

the Health Secretary, although there is no mention of the word poverty in the whole of the Green Paper. William Waldegrave states:

Achieving our targets calls for the involvement of all those with a concern for health, including the NHS in health promotion and treatment, schools in educating young people and local authorities across a range of statutory services ... There is also much for the citizen individually to do - not smoking, having a healthy diet, taking exercise.

At last there is an acceptance that everything cannot be left up to the individual and that mutual agreement between the government and the community is required to gain the best results. The paper has been welcomed by the British Medical Association, the Royal College of Nursing and the WHO. The Coronary Prevention Group will also be pleased to know that the paper:

... announces the setting up of an inter-departmental standing committee of ministers to be chaired by Virginia Bottomley, the Health Minister, to ensure that government departments do not adopt policies that are detrimental to health (21).

A COMMUNITY PROJECT

Criticisms that the government's Green Paper on health promotion is long overdue are backed up, not only by comparison with other world countries, such as the United States, Canada and Australia, but also by a country much closer to home - Wales. The Heartbeat Wales Campaign was launched back in 1985 as a massive project designed to cut down the number of deaths caused by heart disease, and the

Health Promotion Council for Wales, established in 1987, with a more than adequate budget, creates a generous financial backing for the whole project.

Wales has 'become something of a model' (22) in that:

More so than any other community project, it has recognised that health is related to social, economic and physical environments ... realised that people are unlikely to eat healthier foods unless they are readily available and affordable (23).

Its key to success, then, seems to be the adoption of a positive approach to health promotion, with an emphasis on what can be gained through adopting healthier lifestyles, for example, eating more fruit and vegetables, rather than dwelling too long in a negative fashion on the things that people should not do.

The campaign, for example, has persuaded the supermarket chain, Tesco, to co-operate with its objectives so that it has:

... reduced the fat, sugar, salt and additive content of its own brand products, printed detailed nutritional information on its labels and has seen more sales of fish, wholemeal products and pulses since these changes have been made (24).

The prices are not necessarily cheaper than before but the supermarket holds promotion days when it then cuts the costs of certain goods.

John Catford, Professor of Health Promotion, University College of Medicine and Chief Executive of the Health

Promotion Authority, believes that positive results have been achieved since the start of the campaign in 1985:

There have been some major changes in eating behaviour, more people are buying low-fat products and fruit and vegetables. Between 1985 and 1988, the amount of fruit in the diet that people ate most days increased from 20 per cent to 40 per cent (25).

Here, then, is a perfect example of how community and authority have been working together in order to make healthy options accessible and affordable, although the results of their main objective, to reduce the number of deaths caused by heart disease, will not yet be seen for at least another decade.

IMPLICATIONS OF THE GREEN PAPER

Admittedly, the Heartbeat Wales Campaign is aiming towards a much smaller population than the health targets proposed by the English government, which must make their task comparatively easier in a number of ways.

One of the main differences between the two campaigns is that the Green Paper is a political document and there is a danger that it could be seen as being politically oriented rather than health oriented, especially due to the proximity of what looks like being a hotly contested general election. It is sincerely hoped that the document is not merely a vote-catcher, especially when it is considered that the government has undergone a U-turn since the publication of the Black report in 1980, as it was the same government in power at the time, and that it has genuine implications for the health of the British nation.

Another question that should be asked of the Green Paper is how will it actually help the lower and less educated

classes? The consultative paper does not make it clear how the proposed targets are to be met or what methods will be undertaken to promote the health of the nation. Labour, for example, in their health promotion plans, have stated that they will introduce random breath-testing, ban tobacco advertising and reintroduce free eye tests and dental checks (26). Even if, when the recommendations become legislation, the government succeeds in promoting awareness across all of the social classes, what can people do once they are aware, if they cannot afford to put their newly-acquired knowledge into practice? The Welsh claim that they are managing to overcome such barriers, but, again, their campaign is on a much smaller scale.

It will be very interesting to see just how effective the British government's plans are when they are finally enacted in following in the footsteps of the Welsh success.

IMPLICATIONS FOR LIBRARY AND INFORMATION SERVICES

The World Health Organisation Regional office for Europe stated, in 1985:

Health for all will be achieved by people themselves. A well-informed, well-motivated and actively participating community is a key element for the attainment of the common goal (27).

Hence, it is believed that people can be made more conscious of their health in order to help themselves, as long as they are well-motivated and well-informed. One way in which this can be achieved is through legislative help from the government, a matter which has been discussed previously in this chapter. Another way is through health-educators, such as general practitioners. It seems to be the trend, however, that the term 'health education'

is being gradually replaced by the term, 'health promotion', a movement which may not be altogether beneficial for the informed public. Trained health educators are beginning to be replaced by nurses in their newly-assigned role as 'health education facilitators' (28). Whereas for health educators it is their 'raison d'etre', nurses are not being fully trained as health educators until the full recommendations of Project 2000 begin to take effect.

A third way to achieve a well-informed public is through the network of library and information services across the country which are key services in helping to disseminate important information amongst the community. The concept of health information for the consumer has, therefore, without doubt, major implications for such services, especially since it is soon to be backed by government legislation. These implications will be outlined as very important issues in Chapter 8.

SUMMARY

This chapter has described the main factors associated with the rise of health promotion up to its most recent developments in 1991. I cannot predict the outcome of the Green Paper, 'The Health of the Nation', but it will certainly have implications for library and information services in the provision of health information in the future and their role in raising the public's awareness of the issues.

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CHAPTER FOUR

WRITTEN INFORMATION

Over the past twenty years there has been a steady increase in the wealth of health information which is accessible to the public in a variety of different forms. The emphasis is turning rapidly and relentlessly away from the doctor to the rights of the patient. The Guardian, for example, in an article which foresees the obligation of 'patient package inserts' or detailed leaflets, which will be provided with all prescribed drugs by 1992, states:

There is an alarming public ignorance about drugs and a corresponding failure by the medical profession to convey vital information. This may be because until recently the patient has played a passive role, complying with instructions without question. But the growth of consumerism has changed attitudes (1).

Consumers are now demanding information on all aspects of health, ranging from coping with long-term diseases to what kind of alternative medicines are available. The emphasis is very much on the free access to information.

But with such an abundance of information, is there a danger of over-loading the consumer? This chapter will examine one of the possible effects of written health information: whether reading about illness helps to significantly reduce anxiety for the patient concerned.

THE GROWTH OF POPULAR HEALTH LITERATURE

One way in which the movement away from the doctor and

towards the consumer can be seen is in the large amount of mass circulation magazines and newsletters which are now available on newsagents' shelves all over the country, ranging from specific health magazines, such as *Health and Shape*, to general interest magazines, such as *Cosmopolitan*, *Good Housekeeping*, and *Reader's Digest*.

The May, 1991 edition of *Cosmopolitan*, for example, issued a 'Vital Health Guide' in conjunction with Boots the Chemist, which included the following introduction by the editor:

We know that health and well-being are high priorities for the Cosmo reader. We also know how keen you are to take responsibility for your own health. After all, when you are charged with energy and enthusiasm, you can make the most of your life (2).

The message is one of optimism and positive thinking towards health which will lead to a better quality of life overall. It seems that the promotion of health certainly means big business for the popular health literature in general. Rees claims:

The explosive growth of the popular health literature is a response to the public's voracious appetite for health information and reflects an increasing sophistication of the health care consumer (3),

at a time when

.. the self-care movement and readily available medical information have decreased the medical profession's exclusive role over specialised medical knowledge (4).

One of the most important roles for such magazines is that they include information about alternative or complementary medicine, such as acupuncture or herbal remedies. Today's consumer is becoming increasingly able to make informed choices and decisions about health matters in an age when freedom of information is top priority.

The popular health literature is providing the consumer with access to a diversity of information in a form which is readable, easily accessible and reasonably inexpensive to buy.

LEGAL DEVELOPMENTS IN THE ACCESS OF HEALTH INFORMATION

In addition to the growth of popular health literature, the consumerist movement has also experienced legal changes within the last ten years which has affected access to individual medical records and medical reports made by their doctor for employment or insurance purposes.

The Data Protection Act of 1984 has, amongst other things, given patients the legal right to have access to their medical records which are stored in a computer. In a study carried out by Melville in 1989 (5), he found that patients in a general practice gave a positive response to receiving a copy of their medical record. He gained a slightly better response from patients who received a summary of their record, mainly because it was easier to understand than the record itself. In his review of studies written on the subject, he also found that:

At a health centre in Vermont, where patients could read their medical records, 97% felt less worried about their health as a result (6).

The irony of the Data Protection Act is that, although patients now have access to records on computer, there is still no legal right of access to all manual records. Since many surgeries may hold information on both computer and manual records, the legislation, despite being a step in the right direction, may not be as effective as at first appears.

A more recent legal development is the Access to Medical Reports Act of 1988. The Act states that an individual has the right to see any medical report written by a doctor on the individual's behalf for employment or insurance purposes, as long as it has been written within the six months prior to the request being made. The individual must at least consent to the report, even if he does not wish to read it, before the document is supplied. He can also

request the medical practitioner to amend any part of the report which the individual considers to be incorrect or misleading (7).

This part of the Act sounds fine, but it is the exemptions which render its contents rather controversial. They read as follows:

A medical practitioner shall not be obliged to give an individual access ... to any part of a medical report whose disclosure would, in the opinion of the practitioner, be likely to cause serious harm to the physical or mental health of the individual or others or would indicate the intentions of the practitioner in respect of the individual (8).

In other words, the whole question of whether to give patients access to their medical reports is still open to the discretion of the doctors concerned and by no means leaves the power in the hands of the patients, as the Act

first implies.

There has also been the thought that:

... simply issuing a copy of the record to the patient without explanation or support may promote no positive effects on the practitioner-patient relationship and might, in fact, be harmful and have negative effects (such as arousing fear in response to record entries which the patient does not understand) (9).

This may be so, but there have been few studies claiming adverse effects on patients, with most of them encouraging access to medical records if so desired. It appears that the Access to Medical Reports Act needs to be amended further if the patient's right to know is to be absolute.

SURGICAL INFORMATION

There is wide and varied support for the idea that patients should be given as much information as possible about their health. Nowhere is this more important than in a hospital setting where surroundings and procedures are often very unfamiliar to the patient and information can serve to reassure and help to make the patient feel more in control of what is happening. As Hawkins states:

Most patients, especially those in hospital for the first time, need to be informed about even the simplest test because they have no knowledge of what it entails, and it is the expectation of the unknown which is so upsetting ... Patients are less anxious if they know what is expected of them (10).

Helen Dunkelman agrees wholeheartedly with such a sentiment

in an article which highlights the confusion many hospital staff have in the quality and quantity of information which should be given to patients waiting for an operation:

... The information given by the medical team may be inconsistent, perhaps due to lack of consultation or to disagreement on exactly how much information should be given. Indeed, there may be no set procedure for determining which member of staff is to give such information (11).

Although this article was written in 1979, and the situation of giving information to pre-operative patients may have improved since, I feel it may highlight some of the problems which still exist today. Whose responsibility is it to inform patients of what will happen during their stay in hospital? Is it the doctors or the nurses or a combination of both? Dunkelman suggests that an alleviation of the problem she encountered during her study would be to supplement verbal communication with written information, especially since she found that:

... half of the patients asked were apparently ignorant of the nature of their operations and why they were being performed, even though they had consented to undergo them (12).

This is indeed an alarming scenario, and one which we would hope not to encounter in hospitals today, when communication between medical staff and patients is thought to be of utmost importance for the well-being and recovery of the patient in general.

THE BENEFITS OF IMPROVED COMMUNICATION

Dunkelman was certainly in tune with today's thinking when

she suggested written information as a supplement to verbal communication. Ley claims, almost ten years later, that:

... the commonest form of supplementary information provision is a leaflet, booklet, or other form of written material ... there is good evidence that such written information can aid the communication process (13).

He has also summarised some of the possible benefits of improving communication with written information. These include:

- a. greater patient satisfaction
- b. better patient co-operation with treatment regimes
- c. reduced anxiety and stress
- d. quicker recovery from surgery
- e. shorter lengths of stay in hospital (14).

Such benefits are worthwhile from two points of view. First, if the patient gains greater satisfaction and experiences less anxiety and stress, this can only be beneficial for the patient's mental and emotional state throughout the operation and hospital stay. These effects, in turn, may also lead to better co-operation with treatments which leads to a quicker recovery and a relatively shorter stay in hospital. Although this is again beneficial to the patient, it also helps the hospital regime as shorter hospital stays result in significant economic savings. In today's climate of financial and economic pressure, hospital administrators should especially welcome such benefits flowing from improved

communication.

THE EFFECTS OF WRITTEN INFORMATION IN REDUCING ANXIETY AND STRESS

There have been numerous studies researching how booklets and leaflets on many different aspects of health information help the patients concerned, and whether they do actually assist in reducing anxiety and stress. Although I shall be concentrating on a small number of these studies, they are reasonably recent and are indicative of many of the results gained in the reviewed studies I have read.

An article by Mayberry et al (15) promotes the idea that it is the doctors who have the responsibility of accurately informing their patients about their illnesses and that literature is a useful supplement to their consultations, where the pressure of time may often prevent adequate explanations.

Results from the questionnaires given to patients regarding a leaflet on Crohn's Disease (a long-term chronic disease) proved positive, finding that:

It seems unlikely that patients want to be shielded from unpleasant aspects of the disease and are particularly concerned with the long-term prognosis and risk of developing carcinoma [cancer]. Many patients, however, suggested that such information leaflets should have an optimistic outlook, where possible (16).

Hence, the researchers concluded from the study that:

Information booklets must take account of the needs and interests of patients for whom they are written. They must be developed in conjunction

with as many patients as possible. They are likely to be read by many more people than belong to lay organisations, and have a definite role in the long-term management of patients with such chronic diseases as Crohn's Disease (17).

This dispenses with the view that patients may be better off if they do not know the consequences of a long-standing illness. Knowing that something is wrong but not understanding exactly what it is and the possible risks it may cause in the long term, may actually be more anxiety-provoking than not knowing anything at all about their prescribed condition. Patients desire further information and their wish should not be denied.

A follow-up study was carried out on the Smart *et al* article as:

... concern has been expressed that such booklets could cause undue anxiety and lead to more frequent consultations (18).

Patients were asked one year later about their anxiety levels and consultation rates, having read the booklet a year before. The results showed that:

... 82% of patients thought the booklet valuable and 70% that their awareness of the medical and social problems associated with the disease had been increased. This was associated with increased anxiety in only 13% of patients (19).

Therefore, too much concern about raising anxiety levels after reading a booklet seem unjustified from these results and the display of such booklets in clinics and surgeries was positively encouraged by the authors of the article.

Another study, looking at patients' assessment of a booklet on Achalasia and its effect on anxiety levels, came up with similar results:

Despite ... concern about the long term outlook of their disease, 59% of patients felt no increased anxiety after reading the leaflet. In the minority who did have a change in their anxiety levels, most experienced a decrease (20).

Although these articles go some way to proving the effectiveness of written information for specific chronic, long-term diseases, they do not include the importance of verbal communication. Verbal communication has been shown to also help reduce anxiety levels of patients worried about an illness or surgery, and it may actually be more effective than only reading a booklet without any emotional back-up from medical staff.

A study by Laine et al (21) assesses the effectiveness of a booklet given to parents of children who receive total parenteral nutrition, a treatment where they have to be fed with the help of a drip or by means other than through their mouth. The study demonstrated that anxiety amongst parents was reduced more in those who received the booklet. The authors give an explanation for this:

The communication of accurate information may diminish anxiety because it enables parents to anticipate events and allows for accurate expectations (22).

The study goes one step further to suggest, from the results gained, that the provision of written material together with verbal communication actually helped to decrease anxiety levels more effectively than verbal communication on its own. The conclusion is, therefore,

that written material is often at its most effective when it is enhancing knowledge, rather than introducing it for the first time, in the case of educational leaflets of the kind described. Parents are described as often being 'nervous' so that they 'forgot to ask questions' or are 'too upset to listen', so that a 'well-constructed educational booklet' provided them with 'information to read at their leisure' (23).

It would seem that written information as a supplement to verbal communication, can be put to good use in a medical situation. As researchers have found:

In theory, written information has a number of advantages. It can be constructed in such a way as to enhance both understanding and memory. The content can be written so as to ensure coverage of all important points, and it also provides a permanent record of the information. This, of course, means that it is available for later consultation should the need arise. A further advantage is that people appear to be favourably disposed towards written information about health matters (24).

There is, however, evidence to show that the expected benefits of written information on health matters do not always occur, and this suggests that there are times when, for some reason or another, the information is not as effective as was initially intended:

... to be effective written information has to be noticed, read, understood, believed and remembered ... these conditions do not always obtain (25).

PROBLEMS OF UNDERSTANDING WRITTEN INFORMATION

Although there has been a large number of studies praising

the merits of written health information in the form of booklets or leaflets, there have also been numerous investigations testing the understandability of a large cross-section of the health and welfare literature, which is intended to be read by the average lay person, with significant results.

Davis *et al* (26) discovered in their investigation that in the patient education materials they used for the study there was a large gap between the average patient reading ability and the level of readability required to fully comprehend them. If written information is given to the patient as a necessary supplement to verbal communication, then their misunderstanding of the text can lead to all sorts of problems, including non-compliance and an awkward doctor-patient relationship as a result:

Patient comprehension is a prerequisite to patient compliance with medical instruction and health education ... Misunderstanding medical words or terms may interfere with all aspects of health care, including history taking, diagnosis, treatment and prevention of education (27).

This can only be of harm to the patient in the long run and it has been suggested that doctors should take more time to evaluate how well or poorly patients will be able to understand written information before a leaflet is given to them. Patients will only be able to share responsibility for their own medical condition if they can fully understand and therefore feel in control of their own condition. Giving them written information which is too difficult to comprehend will only hinder that responsibility and control.

Such problems are particularly important to overcome in an age when patient education is becoming increasingly

important in the hospital and surgery:

Almost as a matter of routine ... hospital patients are expected to read and understand large amounts of written information - admission forms have to be filled out, consent forms signed, and instruction sheets digested. Much more emphasis is being placed on patient education in the hospital, and as patient education increases, the amount patients are expected to read also increases (28).

Unfortunately, some written information defeats its objective of enhancing patients' knowledge by including the medical terminology it should really be avoiding.

Another study carried out in America sought to:

... test the assumption that patients may not be able to read and fully understand the written materials used in hospitals (29).

The results gained were very similar to the ones above:

... the authors concluded that the materials analysed would be difficult not only for the poorly educated or elderly to read, but the general public as well (30).

In order to improve such statistics, the Dixon and Park article just described suggested that the doctors, themselves, should take more care in evaluating their patients' ability to read written health information and this should definitely be so in the case of a GP setting. Dixon and Park, however, suggest that nurses are in a better position to help such a difficult situation:

Nurses, as teachers and interpreters of health information, must be familiar with their patients' reading levels. Since nurses are frequently involved in writing patient information pamphlets, they need to improve their own writing skills and be constantly aware of their audience's potentially limited grasp of the material (31).

As this statement implies, nurses in America may already have an accepted role as health educators, and may therefore be fully trained as such. At the present time, the role of nurses in Britain as 'health education facilitators' is still a relatively new idea and will not be fully effective until the recommendations of Project 2000 are well under way, with educating patients becoming an integral part of the student nurses' training programme. It still remains, however, that all authors of written health information for patients should be aware of the kind of readability levels the average lay person is likely to fully understand, and to produce the literature accordingly.

Apart from the recent articles I have described, Ley has reviewed a large number of similar studies and come to a similar conclusion. He believes:

... it seems likely that considerable numbers of leaflets and other documents for patients are at too high a difficulty level. The moral is obvious. Anyone producing written information for patients should routinely apply a readability formula to it. If readability is low, then the material should be rewritten (32).

He describes readability formulae as

... regression equations for predicting difficulty of text from such predictors as word

length, sentence length, and frequency of occurrence in written language as a whole of the words used in the text being measured (33).

Those most often used to measure the understandability of written health and welfare information have been the Flesch formula, Dale-Chall formula and the SMOG Grading, where SMOG stands for 'Simple Measure of Gobbledygook'. Although using a readability formula to measure the understandability of a text does not always guarantee that the leaflet will be easy to read if the marks are low on the scale, it is still a useful rough guide and will tell that something is definitely wrong if the marks on the scale are too high.

For written health information to be effective, especially since it is such a popular source of information amongst patients generally, authors must be constantly aware of the audience they are going to attract and apply such knowledge accordingly. If this occurs, greater patient compliance and a consequently improved doctor-patient relationship, so important for the effective treatment and overall satisfaction of the patient, are bound to be achieved.

SUMMARY

There are undoubtedly many benefits in improving doctor-patient communication, especially if written information is used to enhance verbal communication given during consultation times. As yet, little, if any, definitive research has been undertaken to assess the effectiveness of reading about illness without the emotional support of a doctor or a member of the medical profession. Also, the problems of who should be responsible for giving information to patients are far from solved and more

research is needed in this area, too. Medical booklets and leaflets are very useful as long as the patients are able to fully understand their contents and this is a major concern for the effective provision of written information to consumers overall.

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CHAPTER FIVE

THE EFFECT OF PRE-OPERATIVE INFORMATION ON POST-OPERATIVE STRESS AND RECOVERY

As mentioned briefly in a preceding chapter, there are now a number of investigations concerned with the effect that the provision of pre-operative information may have on post-operative recovery. There is a growing belief that improved communication between doctor or nurse and patient can ease anxiety before an operation - a process which can positively affect the patient's mental and physical health during the recovery period.

Such extraordinary research findings should, no doubt, command keen interest amongst the medical profession and health field in general. The news has certainly gained the attention of the more general media, as *Cosmopolitan*, a women's magazine states on the 'health reports' page:

... if you are to undergo surgery of any kind, it seems that the more knowledgeable you are about what will be done, how you will feel afterwards and the more you are able to relax and make the best of it, then the less pain you are likely to feel after an operation. Also, you'll suffer from fewer post-op problems and will be able to leave the hospital much earlier (1).

A patient is likely to cope better with having to undergo an operation if he is given sufficient information before hand about what the operation entails and its possible after-effects; being able to anticipate an event is more beneficial when having an operation than being kept in the dark as to what is to happen during and after the event.

Anxiety

There is no doubt that all patients, to varying degrees, must experience anxiety when they are admitted into hospital for surgery. It is not surprising when worries about the operation itself and having to go under general anaesthetic are exacerbated by the unfamiliar surroundings of the hospital ward and alienation from family, friends and normal daily routine. Anxiety has been defined as 'an emotion based on the appraisal of threat' and that it results:

... when a person is unable to fully comprehend the world about him. Information received by the sense organs is necessary for comprehension, but the perception of this information is the crucial factor ... (2)

and, as hospitals are perceived by most people as frightening places, they are therefore bound to be anxiety-provoking.

Lazarus (1966) has described six varieties of psychologically stressful stimuli:

1. uncertainty about physical survival
2. uncertainty about maintaining one's identity
3. inability to control the immediate environment
4. pain and privation
5. loss of loved ones
6. disruption of community life (3).

Most of these are likely to be experienced by patients when they are admitted to hospital for an operation.

Feelings of loss of control due to lack of familiar surroundings and daily routine can also result in feelings of helplessness, an emotion which has been described as a component of anxiety:

If a situation cannot be interpreted, then it cannot be dealt with, and the individual experiences helplessness. Helplessness is also associated with the inability to anticipate events (4).

The anticipation of events for patients is impossible without the provision of adequate information to complete the picture of their condition, treatment and recovery.

Therefore, it is not so surprising that anxiety, which has also been defined as 'a fear of the unknown, as disproportionate to the threat involved in the life of the individual' (5) is one of the most common reactions by ill-informed patients to illness and surgery.

Research

Boore undertook an experimental study to find out the effects of the pre-operative preparation on post-operative stress, and in her review of the literature concluded that:

... the aspects of hospitalisation perceived as very stressful by patients are related to a lack of communication of information, or a lack of communication in a meaningful way, on the part of hospital staff (6).

Not only did her project demonstrate that good preparation and information provision before an operation reduced stress levels in the patients concerned after operation, but it also indicated that the probability of the patient gaining a post-operative infection was lowered. Her research linked the psychological state to the physiological state of an individual.

Boore offers a scientific explanation for such a link:

It has been demonstrated that anxiety is associated with alterations in physiological function, including an increase in the secretion of corticosteroid hormones, which results in a number of biochemical changes in the body. Therefore, it is possible that the pre-operative preparation can reduce the degree of biochemical change after operation, and aid the patient's recovery (7).

What Boore recommends as a result of her study is that nurses should be trained in being able to recognise anxiety in patients and hence be able to deal with it accordingly. Over ten years later, this sentiment is again being reflected in the nursing literature. In an interesting article by Jill Swindale, she states:

Helping patients cope with stressful events is recognised as one of the nurse's most vital and special responsibilities (8).

The nurses traditional role, often seen as remaining as detached from the patient as possible, is becoming increasingly threatened as research shows that 'patient outcomes can be significantly influenced by nurses giving pre-operative information' (9).

Swindale promotes an individualistic approach towards health-care, as each patient's anxiety will be provoked by different aspects of the hospital stay which will manifest itself in different ways. The nurse must be able to recognise these signs in order to reduce their anxiety, wherever necessary:

The need to consider problems and concerns relating to anxiety from the patient's perspective is complimentary in a relationship which is based on trust and respect between nurse and patient ...

and she continues:

... the nurse's role is to observe reaction, to understand it, and to take the patient's feelings into account when planning care (10).

It is apparent that the provision of information to patients before operations or treatment is becoming an increasingly popular notion throughout the medical profession .

Problems

It is positive that such a discovery is beginning to be accepted, yet there are still many problems to be overcome before the acceptance of such ideas become effective in practice. Colin Gray, in his article on patients' perceptions of anxiety, believes that:

... the need for information, while it cannot always be presumed, is of principal importance in reducing anxiety (11).

He states that several researchers have shown that some patients gain some comfort out of not knowing what is going to happen to them, thus reassurance and information cannot follow one single procedure and must be tailored towards the individual patient.

For example, many researchers, in studying the effects of information given to patients, have divided the information into two categories - procedural and sensory - suggesting that some patients benefit more from one kind than the other. Gray, in his literature review, found that:

Qualitative studies, in which procedural information (i.e. descriptive) was given to some patients and sensory information (i.e. with reference to feelings that would be experienced) to others, have shown that sensory information has more effect on recovery. However, a combination of sensory and procedural information was most effective in reducing anxiety (12).

In general, though, Gray's study did find that:

... therapeutic discussion is nearly non-existent, which is unfortunate as nursing intervention was rated by 33% of patients as the factor that was most comforting and reassuring (13).

Therefore, although the patients are expected to benefit dramatically from such research findings, there seems to be a tremendous amount of pressure on the nursing profession to provide the desired results. The outcome of the combination of Project 2000, the 'Working for Patients' White Paper and 'The Health of the Nation', Green Paper will be interesting in terms of the demands made on the nurses' recently acquired role and the subsequent consequences this will have on hospital patients in the

long run.

Elaine Kempson's Report, 1987

In a response to the large number of studies demonstrating the beneficial effects of giving information to patients, Elaine Kempson compiled a report which was completed in 1987, reviewing the health information needs and services of the consumer (14). It is an important project to consider with its overall aim being to:

... identify the nature of consumer health information needs and to evaluate the different means by which they can be met (15).

The study is divided into two parts, with the first part concentrating on:

- the nature of health information needs faced by the general public;
- how they set about meeting them; and
- the type of service which would best meet the needs (16).

The second part concentrates on a detailed evaluation of the Health Information Service (HIS) at Lister Hospital in Stevenage.

The report can be labelled a key study as not only does it promote the existence of already established health information services for medical staff and consumers alike, but also highlights the problems experienced by the HIS at Lister Hospital and suggests possible improvements for the future.

The group discussions, undertaken for the study, amongst consumers and medical staff, are also very enlightening and contribute greatly towards understanding what kinds of information consumers desire and the problems often encountered by medical staff in giving them that information.

The consumer group discussions, which consisted of people who were likely to have needed some kind of health information fairly recently, enabled Kempson to discover that:

Patients are given most of the information orally and at a time when they are physically and emotionally unable to assimilate it. Further information is usually then given mainly in response to questions, yet patients believe that the health care staff are too busy for them to be bothered (18).

Many people would undoubtedly agree with this sentiment and it certainly implies the importance of written information as a supplement to oral communication. In trying to find out specifically the kinds of information people require, Kempson discovered:

The group discussions ... showed that people wanted both to reduce their anxiety and to enable them to cope with either self-care or nursing relatives. they were only too aware of how busy health care staff are and felt that if they had a better understanding of things, they would be better able to cope without constantly pestering the doctors and other staff (19).

The Acorn Project

The desire not to bother the doctor or nursing staff

because they seem to be too busy is common, even though they are supposedly there to help the patients whenever possible.

The Acorn Project, a research project currently under way, is not only attempting to dispel such a view about medical staff in hospitals, but it is attempting a unique study to this country in the hope of improving doctor-patient communication and to subsequently put into practice appropriate strategies that link information, anxiety and post-operative recovery.

The research is taking place at St Mary's Hospital in the Isle of Wight and is a joint project between the Wessex Help for Health Information Service and the Isle of Wight Health Authority. It is being funded by the Department of Health for one year (1990-91) in order to develop quality initiatives. The funding will be used to:

- establish and staff a patient education resource centre in St Mary's Hospital, Newport;
- provide tailor made information packs for all patients in one model 'health promoting ward', giving details of their condition, treatment and care;
- ensure that patients have continuing access to information about self-care, healthy life-styles and community resources after discharge;
- develop training programmes for nursing and other staff to enhance communication with patients;
- evaluate the effectiveness of these patient education activities by comparing the health status and behaviour of patients who have passed through the model ward with a control group from other wards in the hospital (20).

Bob Gann highlights the significance of such a project:

Some of the most important moments in people's lives are spent in hospitals, yet they can be frightening and impersonal places where patients experience a loss of control over their own lives. Some of this alienation can be overcome through the creation of more attractive and homely environments; another important element is improved communication and information so that patients understand what is happening to them (21).

Another important element to the project is the emphasis on re-maintaining links in the community once a patient is discharged from hospital, and the fact that relatives and friends are also given information so that they may effectively care for the patient during their recovery period at home.

The Planetree Project

The Acorn Project is based on work carried out at the Planetree model hospital project in San Francisco, USA:

Planetree Unit at the Pacific Medical Center aims to break down the impersonal authoritarian approach to health care and to demonstrate that patients recover faster and at less cost in a humane environment where patients and relatives are involved fully in their own care (22).

The project began in 1982 in an attempt to build an effective resource centre for consumer health information. It includes a library of over 2,000 books, has a membership fee starting at \$35 for individuals, and entitles members to a detailed research pack on a topic of the individual's choice.

The Planetree Health Resource Centre has produced a guide to setting up a library of this kind, and it includes a

bookshop and a restaurant, and still claims to be a non-profit-making organisation.

The Centre also houses a model hospital unit where:

... patients are encouraged to study their own medical charts and to write their own reports of progress or setbacks in them. They are given written material explaining every aspect of their illness and the staff are always ready to explain more (23).

Angelica Theiriote, the Planetree founder and President, has stated:

I wanted to bring a humane and healing environment into a high technology hospital, with everything oriented towards the patients' needs and towards providing the fullest possible opportunity for patients and their families to inform themselves and even to care for themselves (24).

It is also the concern at St Mary's Hospital to provide an effective healing environment for its patients and, although its project is not on as large a scale as the Planetree Health Resource Centre, its results will be very important to monitor in the months to follow.

Who knows what this might mean for the future of giving information to patients, hospital stays and recover rates and health care in general - the prospects are exciting and are awaited with eager anticipation.

Summary

Due to the amount of research in this area, it would now seem difficult to dispel the discovered links between information, anxiety and post-operative recovery. Elaine

Kempson's report highlights very effectively the patients' desire for consumer health information and the problems which are inherent in giving it. The evidence required to prove such links is gradually becoming substantial and it is hoped that the results of the current Acorn Project will contribute greatly to this area of research. It may also go some way to encouraging more exploration and to change some of the out-dated attitudes which have been ingrained in our hospitals and medical profession over the past years.

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CHAPTER SIX

THE HEALTH BELIEF MODEL

The health belief model is a theoretical framework developed in the 1960s by four social psychologists - Hochbaum, Kegeles, Leventhal and Rosenstock - in an attempt to explain and predict individuals' responses and behaviour towards health-related matters (1). It has been described as a:

... hypothesis which says that people look for and comply with health-care methods only under certain conditions, and they must have some knowledge of health and the will to keep healthy (2).

The model consists of four main beliefs which need to be taken into account when assessing whether an individual will react positively towards preventive health treatments or not. These are the individuals' perceptions of:

1. susceptibility to and severity of the disease.
2. efficacy of treatment (that something can be done).
3. self-efficacy (one's own ability to deal with the problem).
4. the cost of treatment - in terms of fear, time, money, energy, interest, embarrassment, etc. (3).

When first developed, the model attempted to explain why people should not attend health screenings or immunisation

appointments, often termed preventive measures, when they were provided for the consumer at very little or no cost. It seems, therefore, from the points listed above, that if individuals do not, for example, consider themselves susceptible to a particular illness, or feel they will be able to control it themselves, then they are unlikely to take the time and trouble of travelling to the doctors for preventive measures. As DiMatteo and DiNocola state:

It was hypothesised that an individual will seek to comply with preventive and rehabilitative health regimens as long as the relief from or prevention of disease is seen as more positive than the difficulties encountered and the effort required to attain prevention or cure ... (4).

They continue:

... the individual must also feel threatened by the disease ... and must feel that he or she has some power to overcome it. Thus, in the light of their expectations ... people make decisions (4).

Hence, what the health belief model implies is that it is the subjective beliefs within each individual which govern how they respond to health-related matters and that no single rule can be applied to everyone.

MODIFICATIONS

During the 1970s, Becker, another social psychologist, made additions to what was considered a rather crude model in its original form. He developed it to include people's health motivation, or their concern about health matters and their

consequent willingness, or not, to seek medical attention. He also added 'demographic variables' which are the patient's attitude towards care in terms of the evaluation of the doctor, interaction with health professionals and the structure of the care itself in terms of cost, accessibility and prior experience (5).

He also included 'cues to action' which are divided into internal and external reminders. Internal reminders are the symptoms themselves, which may then persuade someone that they need to see a doctor. External reminders are media presentations or advertisements, for example, or reminders from family or friends, that maybe they ought to go and see a doctor (5).

What Becker's additions have done is to point out that individual subjective beliefs cannot alone predict behaviour towards health-related matters and that, often, outside factors are very important contributory factors towards influencing how an individual may react towards seeking medical care.

THE LOCUS OF CONTROL

A further complication to the theory of the health belief model is that a patient's compliance towards a preventive health measure or treatment can often be associated with the patient's belief that his or her state of health is able to be controlled. Again, as in cues to action, the theory is divided into internal and external locus of control. A patient with an external locus of control believes that reinforcement is under control of other outside forces, such as fate or chance (6). For example:

Many studies have shown that individuals with an internal locus of control ... are more likely to be non-smokers than smokers ... and to quit smoking or modify their smoking behaviour (7).

It has also been found that patients with an internal locus of control are likely to know more about their condition, ask more questions of their doctor and are less easily satisfied with information they are given than patients with an external locus of control (8).

It may be fair to comment that people who wish to read about their illnesses are more likely to have an internal locus of control and will therefore be more able to cope with the information than someone who has an external locus of control. This could be a possible area for future research.

Overall, the health belief model has helped to qualify the fact that 'health-related behaviour and compliance with medical regimens have multi-dimensional causes' (9).

PATIENT NON-COMPLIANCE AND THE HEALTH BELIEF MODEL

It seems that some of the reasons why patients do not comply with medical care or treatment can be explained by theories contained within the health belief model. Although this is useful for those in the medical profession, research has recently suggested that the variables within the model can also be used to predict future compliance of patients, as well as being a means of explaining current compliance or non-compliance.

Ley has found that, although some studies have concluded that

health beliefs do not predict future compliance to medical treatment, most have proved to have positive effects (10).

Although there are a number of factors which affect patient compliance, doctors could use the health belief model to assess how to treat individual patients according to their health beliefs. Perhaps if they were more aware of the health belief model variables, non-compliance in their patients could be reduced and more would be satisfied with the treatment they received.

PATIENT-DOCTOR COMMUNICATION AND THE HEALTH BELIEF MODEL

Ley reports on a study that attempted to prove the theory outlined above, which, in fact, showed the strength of support which the health belief model has gained over the years. In general, researchers have concluded that:

... one source of information about what sort of motivating information should be provided is an examination of the patients' health beliefs. If they do not understand their vulnerability to the condition, its seriousness, or the effectiveness of the recommended actions, then the clinician should provide the necessary information (11).

The study, carried out in 1976:

... showed that the patients of a group of physicians who had had a tutorial on ways of using the health belief model to reduce non-compliance in hypertension had better knowledge of hypertension, better compliance with the medication regimen and better blood pressure control than patients of doctors who had not had the tutorial (12).

This is a very positive result and strongly supports the view that doctors will be able to improve their communication with patients and hence increase compliance rates, if the variables included in the health belief model are taken into account before and during consultation times.

IS IT ALWAYS BENEFICIAL TO GIVE INFORMATION TO PATIENTS?

There have been many investigations into the nature of this question with very different results. There seems to have been a common belief, amongst the medical profession at least, that the less patients know about their condition, the less they will be able to worry about it. This has especially been the case for patients who may be suspected of having a terminal illness, such as cancer, especially if high risk treatment is to be undertaken.

Ley has reviewed a large number of studies concerned with the effects of providing information to patients which have the potential of causing adverse effects, and the effects of giving patients fuller information about their medication. He strongly recommends giving patients as much information about their condition as possible, whatever their illness or treatment. He states:

It would seem fair to conclude ... that the predicted or potential adverse reactions to giving patients full information do not often occur. In general, people want to know even when the news is bad. In view of this, it would seem sensible to provide patients with the information which they say they would like (13).

There are others, however, who would adopt a different point

of view. Individuals have different patient characteristics depending on whether they have an internal or external locus of control. Also, patients have been described as having different styles of coping with surgical stresses and anxiety, 'sensitisers', 'avoiders' and 'neutrals'. 'Sensitisers' are described as highly neurotic, well informed and prepared for the unpleasantness of surgery. They prefer an active defence against their anxiety and stress. 'Avoiders' are patients who distance themselves from negative emotions and are therefore less prepared for an operation or treatment. 'Neutrals' are between these two extremes (14).

Therefore, because patients can be divided into these different categories, it has been suggested that:

information provision [is] ... of less use than at first thought. The technique assumes patients to be uniform, all wanting additional information, but this is not so. Patients with different coping styles benefit in different ways from information provision ... by separating patients into internal and external classes of locus of control, it is found that internals fare better with more general information (15).

This view fully supports the variables which make up the health belief model theory and suggests that patients require information tailored to their own individual requirements.

Ley suggests that patients should be given the information they desire. It may so happen that the amount each patient desires may differ according to their locus of control and particular stress coping style, therefore bringing the two points of view closer to each other than originally suggested. In an ideal world, where patients would feel confident to ask

their doctor as many questions as they so desired and the doctor would always be free to answer them, the problem of tailoring information to the individual patients' needs would be near solution and everybody would be generally more satisfied.

Unfortunately, the world is not quite so straightforward and it will be important to note the results of the Acorn Project, where tailored information packs are being given to each patient on a model hospital ward, in light of such theories which are connected to the health belief model variables.

THE DOCTOR-PATIENT RELATIONSHIP

It cannot be stressed enough how important the doctor-patient relationship is in influencing the health beliefs of individuals. Many studies suggest that, although mass media campaigns may be effective to a certain degree, the most effective health education is accomplished by the doctors themselves. For example, there is much evidence to indicate that:

Mass media messages usually have an impact only when they attempt to reinforce the existing behavioural predispositions of the audience and usually work only when social norms and ties, personal influences, and other mediating factors, do not contract the message (16).

In contrast, a face-to-face encounter makes information less easily ignored, allows for misconceptions to be corrected, can adapt to the patient's own knowledge of self-control in health matters, and makes it easier to persuade (17).

There are many times, however, when patients are far from satisfied with their doctors after consultation. Claire Rayner, one of the country's top 'agony aunts', has certainly discovered this and has put forward some tips for GPs as a result:

Your major fault - if I may be allowed to call it that - is a deep suspicion of everyone's knowledge but your own. You seem to find it impossible to believe that anyone outside the profession can ever have information that you do not (18).

In an age when almost every consumer magazine will have a page devoted to health information carefully researched by medical journalists, there are likely to be cases when the patient will have read an article on a matter of which the GP has not yet been informed. An acknowledgement that this is the case from the doctors themselves may go a long way towards improving the relationship with some of their patients.

Claire Rayner also criticises some doctors for being more willing to prescribe than to listen and for not always asking the right questions. She describes the letters she receives:

Over and over again, they complain to me because you didn't give them the information they wanted; you didn't ask after their family's welfare; you didn't remember what it was you saw them for last time they came 3 years ago; you've forgotten they're allergic to purple pills (19).

Although the image of the doctor as infallible is supposed to have changed with the consumerist movement, patients still

expect rather a lot from their doctors, especially their GPs! They are often still seen as a patient's major source of health information and, indeed, comfort and reassurance when the patient feels particularly vulnerable.

With the doctor still being placed in such a God-like position, health professionals are undoubtedly in a position to influence many people's health beliefs and behaviour, therefore closely connecting the variables of the health belief model with the effectiveness and success of the doctor-patient relationship.

SUMMARY

A dissertation discussing the provision of information to patients would be incomplete without an explanation of the health belief model.

Although only a small amount of research has been conducted in this area, enough evidence exists to suggest that if doctors have some kind of training in how to adopt the health belief model variables into their own communications with patients, not only may patient compliance to their instructions and treatment be improved, but the information that they decide to give each patient and their consequent relationships, may generally be much more effective.

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CHAPTER SEVEN

THE MEASUREMENT OF ANXIETY

In order to find out whether reading about illness significantly helps to reduce anxiety, a measurement of the anxiety experienced by the patients concerned is required. Later in this chapter, I shall be suggesting a possible research project for this topic. First, however, I shall outline a brief overview of the different anxiety measures which are available, pinpointing the ones which are more well-known and therefore more commonly used in practice.

Such a large variety of measures has emerged over the years that they have been divided into many different categories. McGrath (1970) placed them onto three levels: physiological, psychological and behavioural (1). The physiological level has to do with what happens to the body physically when an individual is experiencing anxiety. The psychological level has to do with how the individual is affected emotionally, and the behavioural level is how the individual reacts to people and performs certain tasks.

Another way of classifying anxiety measures is to place them in terms of their generality - as to whether they measure anxiety in general or concentrate on the specific fears and phobias which cause anxiety (2).

Regardless of how the measurements are classified it seems that the most common way of assessing patients is by personality tests and self-reports of their subjective states, where patients are asked to answer set questions from a questionnaire.

THE STATE-TRAIT ANXIETY INVENTORY

There are a number of standardised questionnaires which can be used, such as the State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch and Lushene, 1970). A state can be explained as:

... a condition that holds true now, or at a specified time, but may not hold true for the individual at other times ... (3)

and a trait can be explained as:

... a condition that is permanent, or at least long-lasting and changes rather slow, if at all (3).

It is important that anxiety measures should be able to distinguish between the two. A fear of spiders may be a trait anxiety, whereas a patient visiting the dentist may experience state anxiety, which diminishes once the visit is over.

The STAI is made up of eighteen statements, such as 'I feel calm', which are then answered by way of a four-point scale, ranging from 'not at all' to 'very much so', depending on the current feelings of the patient concerned (4).

OTHER SIMILAR INVENTORIES

The STAI concentrates on identifying patients' current feelings of anxiety rather than trying to assess the general disposition of their characters. This is also true of another inventory called the Multiple Affect Adjective Checklist

(MAACL; Zuckerman and Lubin, 1965):

The MAACL comprises 132 mood adjectives. Subjectives are required to indicate those adjectives from among the entire list which characterise their present mood. A sub-set of 21 adjectives are assigned to Hostility and Depression Scales (5).

Another inventory is the Anxiety Differential (Alexander and Husek, 1962) which, although highly rated, has not been used as much as the STAI. It consists of twenty-eight items which are rated on a corresponding seven-point scale made up of opposite adjectives, e.g. fingers: loose - tight; anxiety: clear - hazy (6).

The Subjective Stress Scale (SSS, Berkun, Biale, Kem and Yagi, 1962) was originally developed to be used in a military field setting but has been found to be very useful in more general laboratory settings:

Fourteen adjectives (e.g. indifferent, worried) are located at various points along the continuum. Their locations are assigned numerically according to mean ratings of association with stress obtained from a military sample. If undergraduate students, or similar research samples are employed, a different set of values are more appropriate (7).

The SSS scale is a useful inventory for its sensitivity and versatility, having been used to measure anxiety in such diverse situations as military manoeuvres and concert performances.

THE MMPI DERIVED ANXIETY MEASURES

The Minnesota Multiphasic Personality Inventory (MMPI) was developed by Starke R. Hathaway and J. Chamly McKinley around 1940, as a result of a large series of research studies in the Department of Psychiatry at the University of Minnesota. It was originally developed for male homosexuality, which was then considered to be a disorder, but was later renamed Masculinity-Femininity (8). To explain it briefly, it consists of five hundred and fifty statements in its final form, which all need to be marked either true or false.

As it is such a large measurement to use and one which takes rather a long time to administer, a number of smaller tests have been derived from the MMPI, namely the Taylor Scale, the Welsch Scale and the Finney Scales.

The Taylor Scale of Manifest Anxiety (MAS) was developed by Janet A. Taylor and is probably the best-known and most widely used of the MMPI derived measures, consisting of fifty items to be answered altogether (9). The Finney Scales are considered important as not only did Finney include a general anxiety scale, but he also included four kinds of anxiety by content: guilt, embarrassment, fear/phobia and obsessive worry (10).

THE CATTELL ANXIETY TESTS

Spielberger has stated:

... subjective reports about emotional states came to be viewed with extreme suspicion because they were unverifiable and easily falsified ... self-report measures such as the STAI may be criticised on many grounds. It may be argued, for example,

that the items are ambiguous and mean different things to different people, or that people do not know themselves well enough to give truthful answers, or that many people are unwilling to admit negative things about themselves (11).

The Finney Scales are important as they use exterior criterion which result in more objective personality tests, as well as attempt to specify the nature of the anxiety being measured.

Another major development in personality testing by questionnaire was founded by an Englishman, Raymond B. Cattell. His tests require people to rate themselves on a list of sixteen qualities, all of which are considered to be 'personality' traits (12).

OTHER METHODS OF MEASUREMENT

Questionnaires could be described as direct measures of anxiety, but there are some recognised measures which are more concerned with observing the subject. One observability measure, for example, is that of facial expression, especially since 'there has been a long history of interest in the relation between facial muscle activity and emotion' (13).

Concerning more behavioural disruptions, it is commonly accepted that anxiety and stress can often affect the performance of complex tasks. Neufeld explains this:

Disruption of motor performance would be expected from 'stress-induced' muscle tremor and/or difficulty in suppressing strong but irrelevant

responses in complex tasks ... concerning cognitive efficiency, stress may instigate 'intrusive thoughts' and/or consume attention ... (14).

A wealth of data related to tasks such as 'errors in copy-editing prose, inaccuracies in performing computer-presented analogies and speech disruption' based on research into the effects of anxiety and stress on performance, has been available for many years (15).

A number of physiological changes invariably occur in individuals experiencing anxiety, such as increased perspiration and pulse rate. Such changes are directly related to the autonomic nervous system (ANS) or the involuntary nervous system, which controls such bodily functions as heart-beat and respiration. There are methods available, normally involving electronic equipment, which attempt to monitor the activities of the ANS in order to measure anxiety (16).

Finally, as 'information-processing is considered to be adversely affected by stress' (17), there are also measures which attempt to assess the information-processing capacity of an individual experiencing anxiety. It is, however, a complicated process which requires 'the consideration of formal (mathematical) models of memory perceptual processes and corresponding experimental paradigms' (18).

THE MEASUREMENT OF PRE-OPERATIVE ANXIETY

From the above description, it can be seen that there are many different methods of measuring anxiety which highlights the difficulties involved in gathering an accurate assessment. As

it is common for patients waiting for surgery to experience anxiety, there is also a measure available which is used specifically in hospital situations, i.e. the Hospital Anxiety and Depression Scale (HAD Scale).

A recent study by Hicks and Jenkins (19) undertook to assess the usefulness of the HAD Scale in measuring anxiety in pre-operative patients. Although it was a newly introduced self-assessment scale when the article was published in 1988, and there was no published data on its effectiveness with pre-operative patients, it has been shown to be successful in assessing anxiety in general medical out-patients.

A group of one hundred day patients filled in the HAD Scale which consists of seven multiple choice questions, regarding anxiety, each with four possible answers. They also had to complete the Multiple Affect Adjective Checklist (MAACL), mentioned earlier, and the Linear Analogue Anxiety Scale:

Patients were asked to indicate on a 100 mm horizontal scale, between the limits 'calm' and 'terrified', how tense they felt at that moment (20).

Despite Spielberger's criticisms about self-report tests, the HAD Scale proved to be an effective measurement of anxiety in this instance:

Multiple choice questions are a familiar part of our modern life and our questionnaire was readily accepted by all the patients in the study. The HAD scale was easily understood and completed correctly by all the patients in the study (21).

It was also found to be a more useful measurement of pre-operative anxiety than the other two scales used in the experiment. Maybe this is because they were not designed specifically for hospital patients, and therefore less sensitive to the specific anxieties involved. Observation methods by the anaesthetist were also found to be 'a crude method of assessing pre-operative anxiety' (22).

A SUGGESTION FOR RESEARCH

As previously stated, there seems to have been no significant research on whether reading about illness is less effective and more anxiety-provoking when the individual concerned has no emotional support from a GP or medical professional. I shall, therefore, briefly outline a possible study for research which may go some way towards shedding some light onto this otherwise undiscovered area of patient information provision.

The study would compare people who visit a Health Information Service asking for information without any emotional support from GP, against those who are encouraged to read about illness in the GP setting where a patient information collection is available and there is medical support.

Figure 1 illustrates an outline of the suggested study. GP patients are divided into those who have access to a patient information collection at the surgery (1) and those who may have to visit a health information service if they want to read more about their illness (2). They can be compared against the non-GP patients who independently visit the HIS (3). The control group is made up of those GP patients who, after consultation, do not require any more information, either because they are too nervous to learn more (4) or

FIGURE 1: OUTLINE OF SUGGESTED STUDY

because they are satisfied with their diagnosis and treatment (5).

When measuring anxiety levels, it is suggested that a general anxiety scale is used; for example, the State-Trait Anxiety Inventory (STAI) or the Multiple Affect Adjective Checklist (MAACL), both before the information has been read and again afterwards so that the effects of reading the information on the individuals' anxiety levels can be recorded. The control group follow-up test would be administered shortly after consultation, to measure whether the time-lapse has made any difference to their original anxiety levels and to provide a comparison with other group results.

Subsequently, the results of the anxiety measures may be compared between five different groups:

1. GP patients who are encouraged to read more about their condition from the patient information collection at the surgery.
2. GP patients who may be dissatisfied with the information provided by their GP and need to visit a HIS to read more about their condition.
3. People who visit a HIS without any emotional support or primary information from a GP who wish to read about a certain condition.
4. GP patients who do not wish to read further information because they are too anxious about what they might discover.

5. GP patients who are satisfied with their diagnosis and treatment and therefore require no more information.

The hypothesis for this study would be that patients provided with written information about their illness and its treatment and who do receive emotional support from their GP or medical professional will have reduced anxiety levels.

To be both valid and reliable, the study would need to be longitudinal in nature, drawing data from a wide sample of settings using a representative sample of patients from varying socio-economic backgrounds.

SUMMARY

In this chapter, I have outlined only a small number of the anxiety measures which are available. It is a complex topic and I do not claim to have gone into it in any significant detail, although it is an important background to the possible research project I have suggested. Reading about health-related matters is becoming of increasing concern in today's age of consumerism and freedom of information and the consequences of doing so need to be investigated fully so that it may benefit and enhance the whole area of giving information to patients.

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CHAPTER EIGHT

PROBLEMS AND RECOMMENDATIONS

With today's growing emphasis on self-care and health promotion, we are experiencing a re-emergence of the idea of provision which has, ironically, been around for many centuries. Written information is becoming an increasingly important supplement to verbal communication and research is required to discover the possible dangers of reading about illness without emotional support from a medical professional.

It has been suggested that pre-operative information can ease post-operative stress and recovery, which benefits both the patients and the hospitals alike. Anxiety is a natural reaction towards illness and hospital stays and, if information provision can help to ease it in the majority of patients, it can only be advantageous for everyone concerned.

The discussion so far has concluded that information provision is beneficial to most patients, but there is one major confusion that has emerged: that is, who is actually responsible for giving the information?

In this chapter, I shall highlight some of the problems which have arisen from this confusion in three main areas of concern: the GP setting, the hospital setting and the public setting. I shall then make a number of recommendations aimed at solving such problems and highlight possible implications for library and information services as a result of the growth of health information and patient information provision in general.

Problems in a Primary Health Care Situation

The GP is still considered to be the most reliable source and is the most popular source of primary health information available. It therefore seems very unfortunate that:

In the face of all the obstacles and effective physician-patient communication, some physicians have partially or wholly given over to other professionals (such as nurses) the task of informing patients about their illness and treatment (1).

A GP should be able to listen to patients, communicate well with them and offer information as and when appropriate. If the doctor-patient relationship is healthy, then problems of unsatisfactory consultations should not exist. This is unhappily not always the case.

Information should be seen as central to the success of doctor-patient relationships. Many patients leave their doctor feeling dissatisfied and therefore go elsewhere, such as the public library or local health information service, for the information they require. The possibility of lack of understanding or miscomprehension of their condition as a result may lead to undue anxiety and stress, which, in turn, and may actually make their condition worse in the long run.

Such problems facing patient information provision in this area need to be changed in order to achieve a more effective primary health care system than is currently in existence in this country.

Recommendations

1. All GPs and primary health care specialists need to be convinced that information and good communication is central to their success. If patients leave their consultations feeling satisfied, they are less likely to make additional appointments for the same complaint, and are more likely to abide by the advice and treatment given. This helps the effective and efficient running of the surgery as a whole.
2. It should be mandatory for every GP surgery or health centre to have its own patient information collection. This could be funded by the local authority or the regional health authority, either of which would also pay for a qualified librarian to manage the stock. GPs could then recommend supplementary reading to their patients with full emotional support and encouragement.
3. Good communication with the local health information centre is essential so that the role of the HIS can be seen as a complementary service, not only by the patients, but also by the GPs themselves. If GPs have the knowledge of what information is available, they could then recommend appropriate supplementary reading to their patients not held by the patient information collection in the surgery. One good example is a knowledge of the self-help and community groups which exist in the area which would be of mutual benefit to both the groups and patients alike.

Problems in a Secondary Health Care Situation

In a hospital setting, the problems of who should give

information to patients is rather more complicated and far less obvious than in a primary health care situation.

At present, no-one seems to have the time to give patients the information they require. It is the nurses who are gradually being given the role of health education facilitators through the recommendations of Project 2000, but the results of such a responsibility, and whether it is practicable, will not be known for many years.

Junior doctors could not, during the present system, take on any more responsibilities in the ridiculously long hours they are already required to work. I suspect that many of them would be grateful for the opportunity to spend time talking with their patients but, unfortunately, they get little chance to do so.

One possible solution to ease such pressures is to create more jobs, but in today's economic and political climate, jobs are being cut from the consultants downwards and whole wards are being closed down - a terrible situation for all concerned.

The whole emphasis towards information in hospitals needs to change. Many of the staff often fail to realise the extent to which patients feel anxious from the moment they walk through the hospital doors. The patients are left to figure out, with very little information or direction, how to reach their destination through a maze of confusing and unfamiliar corridors - and this is all before they reach their ward.

Giving every patient in hospital their own tailored information pack, following on from the Acorn Project, is ideal but could not be presently realised with the staffing, economic and political problems that exist within the NHS.

Recommendations

1. Information needs to become an integral part of the hospital environment. If patients recover more quickly by being given information about their illness and operation, it means shorter stays in hospital - pleasing both patients and hospital administrators alike.
2. Every hospital should have a medical library or health information service which caters for patients as well as medical staff. The medical staff could then use it for their own purposes and also recommend reading to their patients. If patients are unable to visit the library, then the information staff, in liaison with the medical staff concerned, could visit the patients with the information required. It would be a complementary service to the medical staff which would enable patients to learn more about their illnesses with emotional support being available at all times.
3. Admittedly, recommendation two would only be successful with those doctors who have a positive attitude towards giving information to patients. One method which may help to encourage patient information provision is to incorporate communication and counselling skills into the training of undergraduate medical students. This is presently a serious omission in most, if not all, of the syllabuses across the country and one which may be adversely affecting their communication with patients once they are fully qualified.
4. To help ease staffing problems, some of the more routine tasks presently undertaken by junior doctors, e.g. taking blood for blood tests, which take up a large amount of time, could be given to trained clinicians or nurses,

leaving the doctors more time to spend on the wards with their patients.

Many lessons can be learned from the Planetree Health Resource Centre in the USA which is the model for the Acorn Project presently being carried out in the Isle of Wight. Although nurses may emerge in the near future to be the main information givers, I fear this may not be enough to create the information-oriented environment that hospitals are now beginning to require.

Problems in the Public Setting

The main problem here stems from the large number of different information centres that are now available for the consumer. These range from public and NHS libraries to health information services and medical libraries. The number is also growing at a very steady rate.

This is admittedly very good for the consumer but as there is no national co-ordinating policy for all the different libraries, there is undoubtedly a waste of valuable resources which could be avoided.

Recommendations

1. A central body is required which would hold details about all the different health information centres in the country. It would set standards for liaison and co-ordination in an attempt to optimise the use of resources which are available. It could be set up as part of the British Library, for example, or by the Department of Health. This would greatly benefit all health

information workers concerned and consequently the consumers themselves.

2. The public library is often the first place that people visit to gain any kind of information. Each main public library should run a health information service which could act as co-ordinator for all the health information services and medical libraries in the district. This would be very useful at a more local level.

With so much emphasis now being placed on health education and promotion, not least from the Government itself through its recent Green Paper, libraries and information services are central to the success of a campaign aimed at disseminating vital information amongst the community. It is necessary, therefore, that they are given as much help as possible to gain a central co-ordinating body which is effective nationally.

SUMMARY

It would be heartening to see a national health service in the future which is based on the Planetree Health Resource Centre in Chicago, where patient information provision is central to creating an effective healing environment. Attitudes and priorities within the health care system need to change dramatically, however, before such a scenario can become reality.

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CHAPTER NINE

CONCLUSION

It has been made clear in this dissertation that the availability and accessibility of appropriate information to patients is vital to sound medical practice. The provision of such information, with additional emotional support from health professionals, can help to ease patient anxieties and thus aid their subsequent recovery.

The arguments for the provision of information to patients are further strengthened by the growth of the consumerist movement and the current emphasis on health education and promotion. The scenario for patients is a positive one and the implications for library and information services concerned with health care are important to consider as it is a growth area that must receive attention. As one job advertisement has stated:

Health care is currently one of the fastest growing areas of library and information work in the UK (1).

There is an acknowledgement of the demand for patient information provision in the library and information field. It is the health professionals who need to understand the advantages that accrue from having information specialists become an integral part of the health care system. But, as Bob Gann, Director of The Help for Health Trust, states, there is an image problem for library professionals to overcome:

How difficult is the task of promoting a service as dynamic, progressive and integrally relevant to the health service, when the image of the librarian is that of a passive custodian of books wrapped in silence censoriously imposed on others (2).

The image of the stereotypical librarian and a general ignorance of the extent to which they can help in a health care situation are two major obstacles which need to be overcome. Librarians are able to gain a broad and objective view of what health information is available, both for the medical professionals and the consumer.

Health is such a rapidly changing field which requires the professionals to keep up with all recent developments, but rarely have they the time to do so. Librarians can be of enormous assistance by scanning the literature and informing medical staff as and when required. Medical staff and information specialists could form a very effective partnership if attitudes towards librarians were to become more positive.

Librarians also have an advantage in giving information to the general consumer. They do not have the specialised medical knowledge of health professionals and can therefore offer information in a form the reader will be able to understand. In this way, librarians would provide an important link between health care and the consumer, thus enabling the medical information to become easily accessible to the community:

... there is a growing realisation that the most common health care is self-care ... Trends in community care are linked to an emphasis in health promotion on the participation of individuals in

their own health. Access to information is the key to individuals becoming full partners in health protection and promotion (3). ✓

Hence, health information specialists are giving the consumer the freedom they require to be in control of their own health care.

Although a large part of this dissertation has been concerned with written health information, the recent growth of multi-media resources should not be ignored. The librarian, who is mainly concerned with written information, must be aware of the growing popularity of the use of audio-visual aids as an effective way of communicating information.

Whatever the form of communication, however:

... it should be acknowledged that the largest reservoir of written information most useful to the consumer is the library system, both public and medical (4).

If this can be acknowledged by both the medical professionals and the consumer, library and information services could become an integral part of the health care system. There are many sources of health information available for the consumer today, but it is co-operation that is now required. The fight for patient information provision has begun but the battle is far from over.

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