

HEALTH AND ILLNESS

Lecture 3

PROFESSIONALS AND CONSUMERS

In the previous lectures we looked at different ideas people have about health and illness and considered also health-care power groups. In this lecture we are going to look at the role of professionals and consumers in more detail.

EXPRESSED NEED

Expressed need is what people say they need; in other words, it is felt need, which has been turned into an expressed request or demand. Expressed needs may conflict with a professional's normative needs. For example, a patient may express a need for a considerable amount of information on his medical condition, and this may be far more than a nurse is able to or willing to give.

How do you know what consumers of health care want?

Individuals Needs Assessment

What health professionals often find when they carry out a needs assessment with a client is that their perception differs from that of the client. Clients' need for information is underestimated and in health care settings, this may mean information is confined to ward or clinic routines. In a study of women's information needs regarding the menopause, it was found that women wanted far greater detail particularly concerning hormone replacement therapy which would allow them to make a more informed choice (Farrant & Russell, 1985 cited in Naidoo & Wills, 1994).

HEALTH-CARE PROFESSIONALS

Controlling Information: A way to guard their position?

Do health-care professionals cling to their special knowledge, and use it to the consumer, and consumer opinion, at bay?

One aspect of inequality between consumers and professionals is that professionals are regarded as having more knowledge and information, which they are at liberty to withhold from clients. This view is upheld by the many studies, which have shown that a major source of dissatisfaction among patients is a feeling of not being kept informed (Cartwright 1964, Reynolds 1978, Royal Commission on the National health service 1979, Kirkham 1983: cited in Bond 2000). While patients may actively seek information, it is the conscious or unconscious control of information by professionals, which creates uncertainty and anxiety as well as a feeling among patients that they are ignored. There

are many alleged patients reasons for not keeping patients informed – not least that they would rather not know – which are used to justify behaviour.

Professionals regularly act on the basis of assumptions held about patients' desire for information, assumptions which can often be quite erroneous (Bond 1978, Madge & Fassam 1982 cited in Bond 2000). The effect of information restriction is to deny responsible status with the implication that the patient is incapable of intelligent choice and self-control.

A major concept in information control is the management patients' uncertainty. As Waitzkin and Stoeckle wrote:

A physician's ability to preserve his own power over the patient in the doctor-patient relationship depends largely on his ability to control the patient's uncertainty.

(1972 p. 187)

Power therefore rests on the control of uncertainty, which in turn rests on the management of information. Davis (1963) distinguished two types of uncertainty. **Clinical uncertainty** exists when there is real uncertainty about clinical matters and when information of this kind is withheld. However, uncertainty can be projected into a situation where there is no clinical uncertainty in order to manage interactions. This is called **functional uncertainty** and may avoid patients demanding reasons for treatment or explanation of events as well as, when the news is bad, emotional or disruptive outbursts. In order to maintain information control, staff may resort to a number of linguistic devices and interactional tactics, including structuring interactions and conveying the impression that time is short, so that the patient feels there is no opportunity to ask questions.

However, since health professionals are privy to the information first, it is they who decide how, when and what to tell patients. As well as not telling, they can invoke postponement, selective information giving, and obvious deception. On the whole, paramedical staff concurs with medical decisions regarding information. While they may express opinions about the negative effect such practices may have on patients, they usually prefer to avoid conflict with medical colleagues by adopting the same stance (Bond 1978, Wilkinson 1991).

Does Nurse Knows Best? Use of Professional Status/Label

Do nurses as health-care professionals have the right to believe that they may know better than other members of society what other people's health care needs are?

Clearly, our training and experience gives us the authority to make the sort of judgement that results from a nursing process evaluation of specific nursing needs, such as the particular care a person with venous leg ulcer requires. At a more general level, nurses must be careful in using their professional label to make a point in a general argument of any sort. Nurses are sometimes prone to make statements using their professional status when in company with lay people.

Example: "Well, as a nurse, I think that irradiating food is a terrible risk."

Now, as people who watch television, read newspapers and even the relevant research reports, any of us is entitled to have his opinion on this particular subject or indeed on any other subject. However, problems may arise if we use our professional status to give our personal opinions extra weight or credibility.

Because the example we used above is much related to health care there are great dangers attached to it. The nurse who made the statement believes that her opinion is more valid because she is a nurse. By making the statement in this way she may also have influenced what any lay people listening think about irradiation of food. In other words, her use of her professional status may affect other people's perceptions of health and health risks. While it would be stupid to deny that professionals have expertise, it is the belief that only professionals have valid opinions or that as professionals their opinions always carry more weight than others, that is a danger.

The Power of Labels

How our views of ourselves as professionals actually affect the way we do our job.

The term 'labelling' refers to a social process by which individuals or groups classify the social behaviour of other individuals. Whether a given label will have meaning within the social group will depend on whether that label is permanent and this, in turn will depend a great deal on whether the person applying the label has the authority to do so. For example, if a man is labelled mentally ill by his spouse or his lawyer this may not be accepted by others in society until a psychiatrist has legitimised this label by diagnosing the behaviour of this individual as clinical depression, or whatever. Legitimation may not occur until he has been referred to a psychiatrist, which reinforces that he is indeed mentally ill.

Notions of "Normal", "Acceptance" and "Adjustment"

Using these notions implies that nurses are using their professional authority to mould public ideas of health and illness through their 'professionally' expressed judgement.

For example, have night nurses, by suggesting sedation for people unable to sleep for more than eight (8) hours' sleep is abnormal? And has the nursing profession contributed to the stigmatisation of people with skin disorders by agreeing to care for them in special wards?

It can be argued that using professional authority is not a bad thing if the ideas are positive and helpful. If they are not they may result in poor health practice and possibly stigmatisation.

Ageism, that is viewing elderly people as a group apart from the rest of us, is an area where public ideas could be said to have been particularly moulded by nursing specialisation. One might argue that some nursing care of the elderly is specifically required because of their age, but consider further. The elderly may have frail bones; so do many other people. Elderly people may suffer from Alzheimer's disease; so do many people in their forties. Indeed the term was originally used to describe dementia in the relatively young. Specialisation in the care of the elderly may have contributed to the general view of elderly people as a problem group.

Nursing specialisation may have played a part in influencing perceptions about health and illness in many years. Psychiatric and mental handicap nursing specialisations, now known as mental health, may have helped to underline the separation of people with these problems from the rest of society, a separateness also created geographically in the siting of such hospitals.

Re-siting groups within the community may help overcome the problem, but will changing the 'label' help? We now have a blanket name of 'mental health', presumably to give a positive image.

THE CONSUMER FIGHTS BACK

Whenever we talk about health we must talk about society, because it is the people who are considered to be healthy or not, and it people who are society (Murcott, 1979). Those with the greatest power, and therefore the loudest voices, generally has their views heeded most. But those with less powerful voices can still influence the way in which health and illness are defined, and the attitudes that society has towards its members.

Routes for consumers to make their views known

In UK there are a number of *statutory and voluntary bodies*, which are active in this field.

A statutory body is a group whose existence is enforced by law.

Voluntary and Consumer groups

There is a plethora of advocacy groups working on behalf of patients in the United Kingdom. Many are disease-based advocacy groups, such as those, which promote the interests of people suffering from AIDS, osteoporosis, diabetes, leukaemia, cancer etc. Others work on behalf of people with mental illness (MIND) and particular patient groups such as the elderly (Age Concern). As well as providing support and information for patients and their families, these groups work to improve the care and services provided by the NHS. In addition, the independent Patients Association works to further the interests of patients in general. Other more formalised mechanisms for public input into the healthcare system are through community health councils, described in more detail below.

Community Health Councils

Community health councils (CHCs) were established in 1974. They provide a link between the NHS and the community, separating the management of service provision from the representation of patient and community interests.

There are currently 207 CHCs in England and Wales (16 health councils in Scotland and 4 health and social services councils in Northern Ireland that perform similar functions to CHCs). Each CHC has around 16 – 30 members; half are local authority nominees; a third are elected by local voluntary sector; and a sixth appointed by the Secretary of State for Health (or Secretary of State for Wales for Welsh CHCs). CHCs are funded from a national budget held by the NHS Executive, but are independent of the NHS management structure, each other and the Association of CHC for England and Wales (ACHCEW). Health authorities are required to consult formally with CHCs on substantial variations in service provision, provide information required by the CHC in carrying out its public duties and arrange an annual meeting between the authority and CHC members.

Although each CHC may approach its task in different way each has a set of shared objectives:

- Promoting local community interests in the NHS
- Promoting improved quality in health services
- Providing a link between the NHS and the public
- Promoting individual rights

In the light of current reforms the future of the CHCs is currently under discussion (Robinson, 1999).

Advocacy

Advocacy is acting on behalf of and in the best interests of an individual or group who are unable to act for themselves. Their inability to do so may be because they do not realise that they can do so, because they lack information or are in a position of fear or because they lack the required skills. An interesting example of advocacy was implemented in inner London, which was concerned about the delivery of health care to non-English speaking women. Many had the difficulty in communicating their problems

and finding their way through the system. They employed a health worker as ‘patients’ advocate’.

Self-help groups

Some diseases and illnesses pose particular problems for care. These problems may be of a material nature, for example the illness may be physically disabling, or psychological. Health professions and lay people provide treatment and help, but sometimes not of the right kind. This has led some patients with illnesses, which produce very particular needs to group together or form their own communities or self-help groups. A self-help group enables the patient to obtain support and advice from others with similar conditions. For many diseases and for many patients this seems to be very important (Robinson & Henry, 1977).

Self-help groups might be seen as filling in for health service deficiencies. For example, a doctor might treat multiple sclerosis as a particular debilitating disease, but for the patient who has to live with 24 hours a day it is an overwhelming experience. Sharing this experience with others with the disease seems to be very helpful, both in terms of advice on physical problems and emotional support. Equally, sharing experiences of the disease can be seen as a sort of protest movement against the biomedical model, which reduces illness to a pathological lesion. In multiple sclerosis, colostomy, epilepsy, diabetes and lots of other illnesses, the disease is more than the biological deficit, and self-help groups enable the wider context of illness to be made salient and for help and support to be provided.

Self-help groups are often very successful. Their membership can number many thousands, and they often produce newsletters and hold meetings for their members. Over the years some groups have been so successful that they have begun to organise themselves on more bureaucratic lines. They appoint a director, have a formal constitution, and raise funds for themselves and for research into their condition. The group comes to have specialised knowledge about the particular disease which very few doctors, if any, are likely to have; and in sponsoring research they can become influential in guiding treatment priorities.

Local Scenario

A number of Nongovernmental organisations (NGOs) exist to promote health-related activities. They range from those having a broad scope of activity to patient self-help groups for specific illnesses. They act as policy advocates, self-help groups and service providers. There is no umbrella organisation to bring these groups together and they are not formally represented on decision-making bodies.

General public

There are presently no mechanisms whereby consumers are represented on decision-making bodies in health care. The draft Health Services Administration Act proposes

that local councillors should be represented on the Council of Health. No consumer organisations exist specifically for health care (Azzopardi Muscat, 1999).

Government Commissions

National Commission for Persons with Disability

This commission is a government-funded organisation, which coordinates activity and services as a platform for the numerous NGOs, which are active both as policy advocates and as service providers in this field.

Government Agencies

'Sedqa'

'Sedqa' is a government agency that has been transferred from the ministry of health to the ministry for Social Policy. It acts as a policy advocator, advisory body and service provider against substance abuse. It also educates about substance abuse.

'Appogg'

In 1994, the Social Welfare Development programme was set up by the Ministry for Social Policy. It was set up by the cabinet of Ministers to work for the improvement of the Social Welfare Sector as well as community development. Through the years, the number of services offered increased not only in number but also in quality. The services within the Agency give priority and focus on children, their families and the community at large thus ensuring that social networks are strengthened and are more equipped in dealing with the real issues that members of the society, especially children and families are facing.

PROPOSED STRATEGY (HEALTH21)

Nongovernmental organisations (NGOs)

NGOs are essential partners for health; they are a vital component of a modern civil society, raising people's awareness of issues and their concerns, advocating change and creating a dialogue on policy; and their role in health should be strengthened. They can provide significant health and social care services to complement those of the public and private sectors, thus mobilising important untapped resources. In particular, their role in fostering self-help, i.e. in helping people suffering from a specific health problem (such as haemophiliacs, diabetics, drug and alcohol users) to take better care of themselves, should be strongly supported. However the strengths and potential of NGOs need to be more closely coordinated with organised public efforts at community or national level to improve the health of population groups. In this NGOs must be seen as true partners. Their involvement in local health programmes also offers an excellent example of local democracy in action – a particular valuable characteristic for countries in transition - and great potential for releasing local resources for health by mobilising strong local community support.

For WHO, a key current priority is to set up more flexible and inclusive mechanisms for creating and sustaining a dialogue with NGOs. This would open up the possibility of

combining WHO's knowledge of the overall needs and options relating to health with the capacities of NGOs for close identification with the issues and the people involved.

NURSES AND SELF-HELP

Oakley (1984) argues that nurses should heed the consumer health-care movement and amend their practice by taking consumer views into account. Professionals should seek to learn from self-help groups and not to lead or teach them.

Support Groups/Self-Help Groups: Implications for Nurses

Madara (1998) wrote:

“In building community and solving neighbourhood problems, one of the most neglected and unrecognised segments of a local community are the variety of self-help support groups that help people deal with stressful life problems”.

This implies that nurses must advocate for the emotional and psychological well being of our clients. One of the first things we can do is to assess the availability of different types of self-help groups in our communities. Based on these assessments, we then can take on the responsibilities of helping with the organisation process of groups based on the greatest needs of the community. Through our work with the clients of the community, we could look for individuals interested in attending a support group, and people that may be interested in helping with the formation of the group and/or facilitation of the group. As nurses, we sometimes have the best view of what needs to be, and how to get it done.

Health professionals and support groups need to exist as a team, helping and reinforcing each other. It is essential that the two work together to best meet the needs of the group members and ultimately the community.

Nurses need to work closely with the self-help groups, as a support to them and an information guide when needed. It is important for professionals to be open to serving as guest speakers and offering suggestions and information when requested by the group. It is just as important to not try to overpower the group, and force unsolicited information on them. It is essential that professionals educate themselves on self-help support groups, to understand the logistics, so that they may better understand what their role should be.

It is also essential that nurses are aware of the functions of all support groups. A visit to different group meetings enables them to observe types of meetings held, the information presented, and the satisfaction of the members. This step will give the nurse an insight on which groups are available and “member-friendly”.

With all the research available on the benefits of self-help support groups, our major responsibility will be to educate our clients on the benefits and encourage

them to utilise these types of groups. Support groups are a cost-effective option for our clients with many positive outcomes. The major implication for nurses related to this concept is to promote utilisation of support groups to community members. Also, through contacts with appropriate self-help groups we obtain a valuable insight of our consumers' opinions.

It is up to each one of us to take action to ensure that consumer opinions of health and illness, and of the care appropriate for each individual, are heard.

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