Focus: current issues in medical ethics

Self-help in health care

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This paper was given at a London Medical Group symposium held at Middlesex Hospital Medical School in May 1979, on 'Self-help groups - England's barefoot doctors'.

Dr Robinson gives a brief history of some of the reasons why self-help groups have evolved and how they work. He also looks at how the 'professionals' can and do relate to them.

As we all know, the relationships between professionals, the public and the government are changing. Money is tight and the range and scale of professional health and social services are being refocused, reorganised and generally re-thought, while medicine, in some quarters, is seen as a threat to health, not merely in the technical sense of malpractice and inappropriate treatment, but in the wider sense of diverting attention from the social and environmental causes of ill health. Closely allied to this is a growing opposition to 'professional' care which undermines the power of the individual to help himself. Not surprisingly, there has been a rapid and substantial growth of self-help groups and organisations which, taken together, now represent a significant feature of contemporary life.¹ As well as the familiar groups like Alcoholics Anonymous,² Gingerbread, and Gamblers Anonymous, there are groups for the mentally ill, the physically handicapped, people who eat too much and for those who refuse to eat at all, for the old and the young, for stutterers and little people, for the blind and the deaf, the worried, the frightened, the lonely and hundreds more besides.

Why is there the need?

Before looking at how self-help groups work, it may be useful to consider why there is any need for self-help groups to do anything at all. In other words, what are the problems that self-help groups are trying to solve? As anyone involved with a self-help group knows, the problems which are shared in any particular group may be physical, practical, mental, emotional, spiritual or social; because in relation to any of these there are people who have some

problem.³ There are those with illnesses such as cancer, or disablements such as stammering, skin blemishes or blindness. There are those with abnormal mental attributes such as feelings of chronic depression, guilt or fear. There are those whose interpersonal behaviour is abnormal, such as those who batter children, make love to them, or choose not to have them; and there are those with some social difficulty such as being a single parent, or homeless, or a mental patient, or divorced.

These are not necessarily major problems. While there may be practical difficulties they may not be insurmountable. As an article in the magazine *Honey* explained, under the heading 'Big Problems for Little People':

The physical limitations of restricted growth are relatively easy to overcome - or at least learn to live with. Clothes can be made to measure and household appliances, and even cars, can be specially adapted to suit the little person's need. Telephone kiosks, door handles and shaver points can, of course, present problems, but Mr Pocock carries a neat briefcase which opens into two steps for just such eventualities.⁴

Clearly, what turns these difficulties into major problems, is the way they are interpreted by the people themselves, or by others. 'What is distressing for people of restricted growth is the way in which people don't respect the fact that little people have an opinion, a view on life and that they want to contribute'.

Despite efforts to ignore the attitudes of other people, for example by saying that 'society doesn't understand', it is easy to see how, for many people, the combination of some particular problem and being looked down on by other people assumes central and overwhelming importance. Not surprisingly, the end result can be to lose all sense of personal value. People describe themselves as feeling guilty and ashamed, feeling inadequate, having no identity, no place in life, distressed, angry and, finally, alone; since in the end there may be a gradual slide into secrecy, seclusion and isolation. How, then, does self-help work for people like these?

How self-help works

Several people have attempted recently to pick

out the core characteristics of self-help.⁵ Killilea lists the following six features of self-help groups which tend to be emphasised:

- a) The common experience of members; the fact that the care-giver has the same problem as the care-receiver,
- b) Mutual help and support; the fact that the individual is a member of a group which meets regularly in order to provide mutual aid,
- c) The helper principle; which draws attention to the fact that in a situation in which people help others with a common problem it may be the helper who benefits most from the exchange,
- d) Collective will-power and belief; the tendency of each person to look to others in the group for validation of his feelings and attitudes,
- e) The importance of information; the promotion of greater factual understanding of the problem condition as opposed to intrapsychic understanding and
- f) Constructive action toward shared goals; the notion that groups are action oriented, their philosophy being that members learn by doing and are changed by doing.⁶

In the literature produced by the groups, great stress is put on the common problem, position or circumstance, colloquially expressed as 'being in the same boat'. 'Being in the same boat' means, first of all, understanding the problems of others, that is: 'knowing what it's like'. It is said that only those experiencing the problem can really understand. As CARE, the Cancer Aftercare and Rehabilitation Society, put it:

The organisation consists in the main of cancer patients – people who know what it is like to have cancer, who know the problems, mental and social, associated with the disease. These people we feel are best fitted to give assistance and help to patients and families before and after treatment.

It is this understanding based on common experience, say the groups, which produces the necessary common bond of mutual interest and common desire to do something about the problem. And the basic ingredient of this 'doing something' is collectively helping oneself.

In addition to helping oneself collectively and helping yourself through helping someone else, great stress is put on the power of 'example'. A point succinctly expressed again by CARE. 'What better therapy than seeing someone who has had exactly what you have got, and who is ... participating in all the normal activities of work and social life'. This emphasis on 'normal activities' is extremely important, because the really successful self-help groups are much more than huddle-together sessions for people who feel discriminated against or overwhelmed by a common problem or by some aspect of late twentieth-century life. The groups which

offer most to their members are those which manage to combine mutual support for those who share a common problem with an opportunity for people to build up a new set of relationships.

The women's self-health groups provide a good example of the way in which self-help can be an opportunity for growth rather than just a refuge from an unacceptable world. An important feature of self-health groups is for women to get to know, understand, monitor, respond to, control and appreciate the functioning of their own bodies. But in the good groups this is only the beginning. The speculum is the instrument for opening up the passage not merely to one's cervix but to a new way of life. Linda Dove, in an article on the Feminist Health Centre in Los Angeles, makes the point. 'Doctors and lovers', she says, 'have had more access to our bodies than we have. We must have power over our own bodies to control our own lives'.⁷ That is the core of the self-help method; to settle from among all the problems that one faces on a clear, understandable and manageable one, to 'find' that one can manage it and so become a person who can control one's everyday problems and, thus, one's life. Self-help, in fact, is a way of life. As the founder of the Association for the Childless and Childfree put it:

... just being together improved morale and made us realise that being childless is not just a case for feelings of misery and hidden inadequacy but a chance for another kind of future based on finding the best in ourselves and offering it to others in whatever way appropriate.

Some people believe that self-help groups are paving the way for a radical change in the way everyday problems are handled, and even providing a blueprint for the construction of a new political order. But it does not take long to realise that, for a variety of reasons, most self-help groups seem neither inclined, nor likely to be able, to accomplish any great social changes.

Limits of self-help

One of the major limits to self-help is that most groups tend to operate with the same view of health and illness as conventional helpers. Problems, however, they arise, are seen to be the responsibility of the individual. The core aim of most conventional help and most self-help is to do something to, or with, people who 'have' problems, in order that they might be better able to find their way around the world as it is. Those self-help groups which look beyond the immediate concerns of their members do little more than press for some adaptation of the current professional or administrative system. They push for recognition of their problem, or for more humane, accessible or competent professional treatment for their problem.

Concentration on individuals and their problems is, of course, an essential feature of the self-help process. But it means, as well, that self-help groups rarely focus their attention on any broader political issues. Their attention is much more likely to be given over to making sure that one is serviced properly, rather than to raising the question of whether one needs the service, or of what changes need to be made in order to make it less likely that the 'problem' which needs servicing will arise at all.

Not only do most groups not look at broad causes of their problems but they may, by their self-help activities, actually make them worse. Self-help groups, it could be argued, provide an excuse for government authorities to avoid fulfilling their obligations. Suggesting that people attempt, with inadequate resources, to build up their own communities or provide their own services may divert them from seeking their full share of the resources of the entire society.

Clearly, everyone involved in self-help groups, however successful they feel they are in alleviating or handling the 'problems' of their members, should ask themselves the following question: 'Is what I am doing likely to increase or decrease the number of people with this problem?' In other words, they must consider the extent to which they collude with the system which caused, maintained, or accentuated the 'problem' in the first place. That is the core dilemma for everyone who gives 'help', whether they are self-helpers or professionals.

Where do the 'professionals' stand?

But what about professionals? Where do they stand in relation to self-help? Professionals are, and always have been, closely involved with even those self-help groups which are considered to be most independent and self-sufficient. A recent study of self-help organisations found that approximately one in three groups were started in close co-operation with professionals. Nevertheless, the nature of the relationship between self-help groups and professionals varies from group to group.

Not surprisingly, some professionals feel very threatened by the growing number of self-help

groups. Others, recognising the value of particular self-help enterprises, have proposed that professionals should become directly involved, that professionals should set up self-help groups and even that universities should train people to do this. Others are less enthusiastic, recognising that this could undermine that one value uniquely cherished by the self-help group; the perceived ability to help itself.

Conclusion

When all is said and done, however, self-help groups are of interest today, not merely because the NHS is short of money – which, of course, it is – or, because the groups are symbols of anti-professionalism – which, of course, they may be – but because some of them actually work. And the sooner professionals, laymen and governments rediscover the simple fact that those who share a certain illness, disability, problem or position in the world have something to offer each other, whether that 'something' is emotional support, technical expertise, refuge from discrimination or whatever, the better it will be for all of us.

References

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