

A survey of lay and professional interest in self-care

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SUMMARY. *This article describes a survey of the extent of interest among medical professionals and representatives and members of patient organizations in expanding the use of self-care by people with chronic complaints. Patient organizations are essentially 'interest' groups, generally centred around a particular handicap or disease. From interviews with representatives from 52 patient organizations and with a random sample of 20 general practitioners, 21 specialists, 20 community nurses and 20 members of patient organizations, considerable interest was found in extending the practice of self-care. There was, however, some uncertainty about how to do this effectively. This study is part of a wider programme of research on the area between conventional health care and self-care.*

Introduction

IN many countries, there are signs of growing interest in finding new ways of helping patients to cope with chronic disease.¹ There is particular concern about the increasing reliance on medication for problems such as stress for which there might be other more effective solutions.²⁻⁵ The day-to-day worries associated with a chronic complaint are seen not only as detrimental to patients (and their supporters) but also as placing heavy demands on doctors. Many medical professionals are, in consequence, now trying to help people cope better with the management of their own disease, for instance through patient education.^{6,7} This means that medical professionals must become more familiar with some techniques of self-care to complement their specialist knowledge.⁸

Concern to find new ways of helping people develop their capacities for self-care (termed 'self-care activating support') gave rise to a programme of research in The Netherlands. This began in 1969 and since 1974 has been located in the medical faculty of the University of Limburg.⁹ Self-care was defined very broadly to include all the ways in which individuals look after their own health, both individually and in self-help groups. An 'equilibrium model', suggesting that patients learn most effectively when they can draw on both the skills and knowledge of medical professionals and the experiential insights of fellow patients, was developed.¹⁰ A programme of experimental groups for patients with various forms of chronic complaint (skin problems, cardiovascular complaints, rheumatoid arthritis and multiple sclerosis) tested this hypothesis.^{11,12} The teaching methods derived from this work, known as 'duo-formula group training', have been tested over 15 years and refined and replicated in other countries.¹³

From these early studies, the need to recognize a new field of research in health care became clear: the area between conventional medical care, provided by doctors, and self-care, pro-

vided by patients themselves. The potential role of medical professionals in helping people to learn how to look after their own health was seen to deserve particular attention. But there was also a need to determine the extent to which patients are interested in learning about self-care techniques and the extent to which doctors are willing to work with patients towards this end. The research described here addressed these twin issues.

This study was undertaken within the wider remit of evaluating an information centre, or 'clearing house' on self-care, located at the University of Limburg — the Medical, Epidemiological and Societal Information Centre. In addition to monitoring the use of the centre, a survey was undertaken to assess the extent to which medical professionals were already cooperating with lay people to develop the use of self-care and the attitudes, knowledge and behaviour with respect to self-care among patients and medical professionals. The research was carried out between November 1983 and November 1986; the three-year period made it possible to assess the impact of the information centre on self-care behaviour and attitudes. This article describes some of the results arising from the first stage in 1983-85; the results of the second (and final) stage will be available shortly.

Method

There were two parts to this study. The first focussed on the attitudes and behaviour of patient organizations with regard to self-care. These organizations are essentially 'interest groups' of patients, generally (although not invariably) centred around a particular handicap or disease and concerned to further public awareness and support for those with the condition. Representatives from a sample of 52 organizations were interviewed using a semi-structured questionnaire. They were asked about the extent of their organization's cooperation with professionals, and their knowledge of, attitudes to and participation in self-care. Self-care was defined broadly, as noted above, to include care by individuals for their own health, either on their own or through groups.

The second part of the study focussed on the attitudes of individual professionals and patients towards self-care. A similar set of questions, again using a semi-structured questionnaire, was put to a sample of three types of health practitioners — 20 general practitioners, 21 medical specialists and 20 community nurses — and to 20 members of patient organizations, 81 in total. The organizations and individuals interviewed were randomly selected from information on the respective populations in the Limburg region, held by the information centre at the University of Limburg.

Results

There were two principal findings from this research. First, there was a strong wish among patients to know more from their doctor about their particular condition and how to practise self-care. Second, medical professionals were generally sympathetic to the idea of self-care, but uncertain about the role they could play in this respect.

Among the 52 spokesmen for patient organizations interviewed, 42 (81%) were familiar with the concept of self-care. Most organizations (67%) said they furthered the use of self-care by providing information to patients and carrying out individual counselling. It was striking that the support given to patients was mainly on an individual — rather than a group — basis. The majority (73%) of the 52 patient organizations had either worked with or had some contact with professionals; only

one quarter (23%) reported no such experience (the other 4% either failed to answer or provided uncodable information).

The results of the interviews with the 20 individual members of patient organizations and the 61 professionals were more complex (Table 1). It can be seen that only 15% of the members of patient organizations had had experience of individual self-care within their organization. Among the professionals, in contrast, experience was much greater; all the community nurses, 90% of the general practitioners and 57% of the medical specialists had come into contact with individual self-care in their work.

The extent of contact with self-help groups or other forms of mutual support was greatest among patients (Table 2). It can be seen that 95% of the members of patient organizations had had some contact with self-help groups through their organization. In addition, among the professionals, 75% of the community nurses, 40% of the general practitioners and 71% of the medical specialists had come into contact with self-help groups or other forms of mutual support. Self-care and self-help were considered to be important means of supplementing traditional health care, affecting physical, psychological and social aspects of people's lives. Most of these respondents (83%) felt that an expansion of activities to support self-care in health was important. They assigned a key role to both professionals and patients in stimulating self-care.

Half of the 20 members of patient organizations reported that they were also a member of a group set up specifically for mutual support among patients (a self-help group). They saw the need for mutual support as an important reason for the emergence of self-help groups. They felt, however, that there could be potential dangers in self-help, most significantly the lack of medical expertise. This suggests that they favoured professional assistance and support in their use of self-care, although they were not clear about the possible role of the professional in this respect.

The professionals interviewed were largely sympathetic to the idea of developing patients' potential for self-care. They felt it

would make patients more aware of their condition and less demanding on professionals, thus proving a means of conserving scarce medical resources. They also considered self-care to be a possible means of reaching a more equitable or balanced cooperation between doctors and patients. But they were also uncertain about how to develop their patients' use of self-care.

About one-third (36%) of the 61 professionals reported that they had tried to work with patient organizations, but only a small number (13%) suggested that they had made a real contribution to any self-care activities. Their collaboration, for the most part, had been limited to referrals, occasionally suggesting that patients attend a patient organization. This was seen as an important factor in providing patients with greater contact with their peers. In all, 82% of the professionals (85% of the general practitioners, 100% of the community nurses and 62% of the medical specialists) had referred patients to patient organizations. None reported any problems following such a referral.

Half the professionals indicated that a possible negative consequence of self-care was that it could be a source of quackery and irresponsible behaviour. Interestingly, the majority of the general practitioners and medical specialists did not perceive self-care as a potential threat to their profession. In contrast, almost half of the community nurses felt somewhat hostile to the concept of self-care among patients, viewing this as a potential threat to their jobs.

Discussion

The extent of interest shown here among patients and professionals in increasing the use of self-care and working together for this purpose is important. Patients clearly want to learn more about how to look after their own health and doctors have a complementary interest in helping their patients to do this. Patients are looking for doctors with an interest in self-care and the relevant skills to help. Doctors, in turn, have growing sympathy towards self-care and are seeking to develop their capacity to respond to patients' demands. What appears to be lacking is not the disposition to work together but the means by which doctors and patients can be brought together to help those with chronic disease. There is a need to find methods of harnessing doctors' medical knowledge and skills, together with the insights of patients derived from experience.

These conclusions have validity beyond the area of the survey and interest in this work has already been generated in medical schools in both other parts of Europe and the USA. There is particular concern to make good use of the resources invested in medical education; enabling doctors to share relevant knowledge with particular groups is seen to be one means of expanding the benefits from that investment. Indeed, as a result of its research and training programmes, the Institute for Self Care Research is shortly to become a World Health Organization collaborating centre on health promotion and coping with chronic disease.

Parallels with the UK can also usefully be made. There is some evidence of growing interest in self-care among ordinary people and growing interest among doctors in finding ways of helping their patients to increase their knowledge and skills. The success of the College of Health, for instance, is evidence for this interest, as is the growth of books on self-care for many individual diseases. As elsewhere, however, it is not simply a matter of bringing the two sides together; there remains a lack of understanding about how to put the ideas into practice. There is relatively little professional collaboration with self-help groups, except for referrals,¹⁴ and doctors do not commonly use such groups as a means of furthering self-care. Patient participation

Table 1. Contact with individual self-care for three groups of professionals and members of patient organizations.

	Number		Total
	Who had contact	Who had no contact	
Community nurses	20	0	20
General practitioners	18	2	20
Specialists	12	9	21
Members of patient organizations	3	17	20
Total	53	28	81

Table 2. Contact with self-help groups or other forms of mutual support for three groups of professionals and members of patient organizations.

	Number		Total
	Who had contact	Who had no contact	
Community nurses	15	5	20
General practitioners	8	12	20
Specialists	15	6	21
Members of patient organizations	19	1	20
Total	57	24	81

groups, which bring doctors and patients together around a general practice, have not been introduced in many areas. Furthermore, although concerned with health education, such groups do not generally serve as a vehicle for conveying systematic knowledge about how to cope with particular diseases.^{15,16}

This research into methods of increasing the capacity of lay people to look after their own health is continuing. This work is particularly concerned with finding the best means of imparting skills in self-care. The 'duo-formula group training' programme developed from this research teaches professionals and lay people to work together to then help other patients with the disease, putting into practice the concept of 'self-care activating support'. Until now offered solely to Dutch doctors and patients, this training is currently being extended to people from other countries. An international workshop toward this end has been arranged for later this year (further information from Dr Bremer Schulte). The particular techniques, or protocols, developed and tested over time deserve further attention in the UK. They offer a systematic approach to lay-professional collaboration built around patients with a particular chronic disease.

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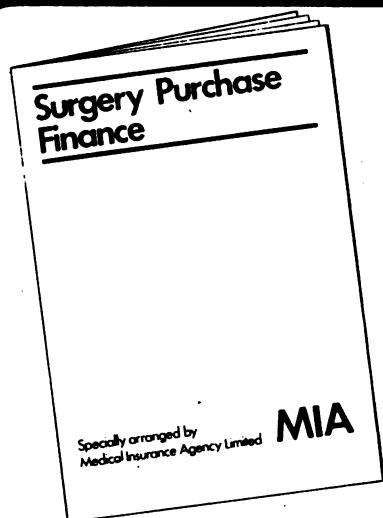
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