Self-help in primary care: preliminary findings of a study in Liverpool

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SUMMARY. Self-help groups are an important, but often neglected, resource in primary care. This paper reports the preliminary findings of a study of the origins and natural history of self-help groups in Liverpool, and considers the role for general practitioners in mobilizing resources to facilitate community participation in health through this diverse, and informal, sector of the health care system.

Introduction

RECENTLY there has been a trend towards self-help in health: there are now an estimated 12 000 self-help and community health groups in the UK.[1] While there has been lively debate about the self-help movement and its relationship to the formal health care sector in the social science literature,[2-4] there has until recently been relatively little on this topic in medical journals.[1,5,6] The majority of empirical studies have focussed on the origins, role and functions of specific organizations, such as Alcoholics Anonymous,[7] and their relationship with specialist health services. Little consideration has been given to self-help groups in a specific locality.

'Self-help', like 'health', is an ambiguous term used widely but rarely consistently. Just as there is considerable debate about the political purpose and virtues of self-help, so there is a variety of opinion about the nature of self-help itself.

The individual and collective involvement by people in their own care has been categorized by Kickbusch and Hatch[8] into: self-care — unorganized activities designed to improve, protect or promote health; volunteer care — organized by traditional agencies; and self-help — purposefully organized activities, including self-help groups, self-help organizations and alternative care (service provision by self-help groups).

Richardson and Goodman defined a self-help group as 'a group of people who feel they have a common problem (and) have joined together to do something about it'.[9] This informal, collective activity extends from groups composed of people with a specific medical diagnosis (and their relatives) meeting for mutual support, to groups whose prime concern is to change their local environment, including their local health services.[10] Similarly, the relationship between self-help and professional health care ranges from those groups which work within the formal health care system, through those which work alongside it, to groups which are explicitly opposed to the professional control of statutory services.[1,11]

This paper reports the preliminary findings of a study of self-help groups concerned with health in Liverpool. The aim of the study was to ascertain the scale and nature of the self-help movement in Liverpool, with a view to raising awareness among health care professionals of the existence of such groups and of their interface with primary care services.

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Method

Identification of the sample

Because of the informal nature of the self-help movement, it is impossible to define the total population of groups from which a random sample might be drawn. Therefore, to identify a broad sample of self-help health groups a combination of methods was employed:

1. Information on the research project was publicized by the local media, including an interview broadcast on local radio.
2. Groups were identified from the lists of local 'umbrella' organizations such as the Council for Voluntary Service and the Community Health Council.
3. Networking methods were used to recruit groups by word-of-mouth from others already involved in the study.
4. A small number of groups were recommended by local health professionals and community workers.

The groups identified were included in the analysis if their catchment area covered all or part of the city of Liverpool; if they were primarily concerned about a health issue; if their control lay with their membership rather than with health professionals; and if they had been identified and interviewed within the six-month study period (1 July to 31 December 1985).

Since the groups were mostly self-selected, the fact that the study was based in a university medical department meant that groups which were more accepting of established medical practice may have been over-represented, and 'radical' groups under-represented. However, the qualitative analysis presented here is not dependent on a truly random sample.

Interview and questionnaire

Each group was contacted by telephone, to establish its sphere of concern and whether it met the criteria for inclusion. One of the authors (E.T. or M.P.) then conducted a semi-structured interview with a representative of each group, usually by visiting the group at one of its meetings. A questionnaire was completed, exploring the origins and history of the group; the trends, size, social composition and recruitment of its membership; the aims, functions and achievements of the group; its leadership and organizational structure; its relationship with health professionals; its available resources; and the nature of its activities.

Results

Of the 43 groups identified three were excluded because they could not be contacted. A further eight groups were interviewed but not included in the analysis because they were run by professionals, not by sufferers, and were involved in information and training about health and self care, for example, Look After Yourself, or offered quasi-professional therapeutic consultations, for example, the Council on Alcoholism. Thus, 32 groups were included in the final study (Table 1).

Table 1. Groups listed alphabetically by sphere of concern.

	Catchment area	No of members[a]
Specific disease or condition		
1. Arthritis Care	City[b]	160
2. Autistic Children Society	Region[c]	35
3. Coeliac Society	Region	300
4. Colostomy Welfare Group	Region	2000
5. Congenital Dislocation of the Hip Support Group	Region	12
6. Epilepsy Association	City	60
7. Haemophilia Society	Region	70
8. Herpes Group	Region	60
9. Leukaemia Care Society	Region	50
10. Lupus Group	Region	80
11. Mastectomy Self Help Group	Region	65
12. Motor Neurone Disease Association	Region	60
13. Multiple Sclerosis Society	Region	300
14. MS Painting Group	City	14
15. Sickle Cell Disease Self Help Group	Region	8
16. Stroke Group (Liverpool)	City	140
General problems		
17. Cancer Care Self Help Group	City	50
18. Cruse (for the bereaved)	Region	150
19. Depressives Anonymous	Region	30
20. Leeson Centre (mental health)	Local[d]	60
21. Maternity Information and Support Group	City	65
22. Miscarriage Association	Region	8
23. National Childbirth Trust	City	40
24. Supportive Help Against Drugs Organization (SHADO) (parents of drug addicts)	Local	80
25. Umbrella Project	City	—[e]
Health issues		
26. Crescent '73 (mental health)	Local	60
27. Croxteth Women's Health Group	Local	15
28. Neighbourhood Health Project	Local	—[e]
29. National Association for the Welfare of Children in Hospital	City	10
30. Speke Women's Health Action Group	Local	20
31. Storrington Heyes Elderly Group	Local	600
32. Women's Health Group (Vauxhall)	Local	50

[a] Number of people in contact with the group at the time of the study. [b] Liverpool and its immediate environs. [c] Wide area, often the whole Mersey region (Merseyside, south Lancashire, and Cheshire). [d] Confined to a small locality in Liverpool. [e] Not able to define 'membership' because acts as lay source of information to whoever contacts.

Sphere of concern

For 16 of the 32 groups studied, the sphere of concern was coping with, or adjusting to, a specific disease or condition (groups 1–16). Nine groups were concerned with general problems rather than individual diseases (groups 17–25). The remaining seven groups focussed on general health issues, often incorporating a campaigning element for improved access to health information or to local health services (groups 26–32).

Catchment area

There was a strong association between the specificity of the group and the size of its catchment area (Table 1). Apart from four groups who had as many participants as they could cater for (groups 1,6,14 and 16), each of the disease-oriented groups covered the whole Mersey region. Among the groups concerned with adjustment to a problem most drew members from the whole city, or a wider area. Finally, there was a distinct set of groups which were neighbourhood-based, and included all but one of the groups concerned with general health issues. These were in the inner city or outer council estate areas of Liverpool and were concerned with wide ranging issues including access to information or services.

Membership

Those groups principally concerned with one-to-one counselling or information, such as Depressives Anonymous, or Cruse, did not have formal membership lists. However, each group estimated the number of people it was in contact with, totalling over 4000 for the 32 groups (Table 1). Apart from six groups concerned specifically with working class localities (groups 20, 26, 27, 28, 30 and 32), membership of the groups was overwhelmingly middle class and the majority of members of all groups were women.

Origins and natural history

Of the 27 groups whose origins were known, 10 (37%) had truly grass roots origins and had been founded by a sufferer, 12 (44%) had been initiated by professionals in the statutory or voluntary sectors, and five (14%) had been started by another group. There was no clear relationship between the nature of a group's origins and its sphere of concern.

Only seven (24%) of 29 groups for whom information was available had passed their peak membership. Twelve groups (41%) had been in existence for less than two years while three had been started at least 20 years ago. Three groups were rekindling their activities, and three others were in decline; in each case the arrival or departure of one key person was the reason for this change. In 15 (54%) of the 28 groups from whom the information was obtained, the current leader was the group's founder; in the remaining 13 the founder had handed over to a successor.

In six cases (groups 2, 20, 21, 25, 28 and 32) the group had become institutionalized: starting as a voluntary activity but later acquiring premises and paid staff, all except group 21 with grants from the local authority, the Manpower Services Commission or Inner-city Partnership Funds. None had been able to meet the demand for its services when relying solely on voluntary resources. Nevertheless all retained the essential features of a self-help group: motivation and control by sufferers, and seeking to solve common problems without professional help.

Resources

Funding. Nine groups received grants from local government and other grant giving bodies (groups 2, 4, 17, 18, 20, 24, 25, 28 and 32) while the remainder were self-financing, raising income from members' donations and fund-raising activities.

Organizations and leadership. Five groups (4, 18, 20, 25 and 28) had staff whose only paid employment was with the group. Five other groups (15, 21, 24, 27 and 32) had the part-time assistance of staff paid by other organizations. The remaining 22 groups were run by volunteers, often from the organizer's home. All of the paid members of staff were women and only four of the volunteers were men.

In view of the size of their catchment areas it is striking that only two of the 16 groups concerned with a specific disease or condition had the benefit of a paid member of staff. The remaining 14 were organized by volunteers, the majority from private homes in medium and high income owner-occupier areas,

and were thus dependent on the organizers' hidden resources of time, money, effort and accommodation (Figure 1). Lacking these resources, those groups in poorer areas concerned with general health issues were unable to function effectively without special funding.

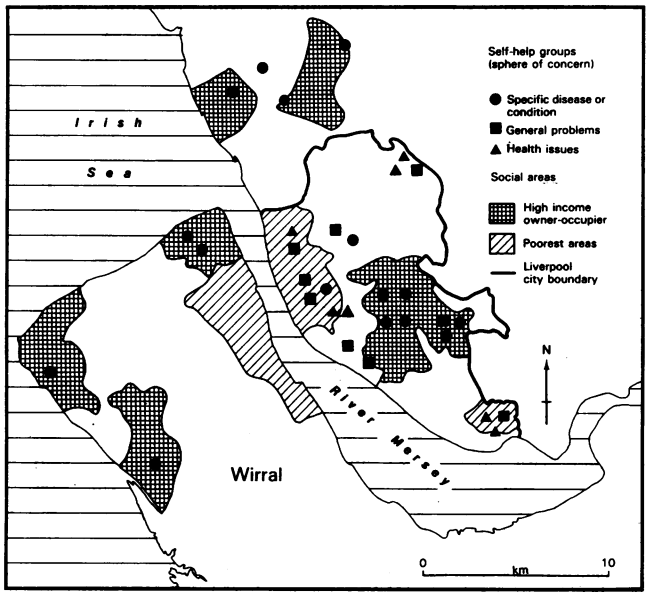

Figure 1. *Map of Liverpool and surrounding area, showing the location of group organizers in relation to sphere of concern of group.*

Premises for meetings. Six groups met in their own premises. Eight groups held meetings in National Health Service or social services premises; in each case access was made possible by the involvement and support of a professional who had negotiated the arrangement on their behalf. In all but one case, the groups permitted to use statutory services' premises were those concerned with a specific disease or condition. Four groups rented premises, eight met in private houses and six met in the premises of another community organization.

Activities

All but two of the groups held regular meetings. The Neighbourhood Health Project was essentially a health information project and the Miscarriage Association worked on a one-to-one counselling basis, but meetings were being planned as the group was becoming more established. Twelve other groups provided one-to-one counselling. Sharing of common experiences was an important aspect of all the groups' work. Many of the disease-specific, region-wide groups gave practical support to their members, advising about appliances, cash grants or diets.

Social activities played a major part in the work of 10 groups, all of which had been organized around a condition which had a major impact on social interaction, either because the condition was physically disabling, for example, lupus arthritis or multiple sclerosis, or because it incurred social stigma, for example, cancer, epilepsy or mental illness. For these groups, the social activities allowed the members to maintain some semblance of normal activity. As one member of the Cancer Care Group put it: 'When I come here, I can leave my disease at the door, I can be just myself, no one feels sorry for me, we are all in it together.'

Interface with professionals

Recruitment. Twenty (63%) of the 32 groups recruited a large number of their members through referrals from professionals, both in primary and secondary care. All seven groups concerned with general health issues recruited members by word of mouth and through local knowledge of their campaign. The majority of groups felt that general practitioners were in day-to-day contact with people who could benefit from the activities and approach of the groups, if only these people knew of their existence.

Professionals made few referrals to those groups whose activities addressed a problem of illicit behaviour or who adopted an approach that was perceived as unconventional and anti-medical, whether in terms of the definition of the problem or of the approach adopted by the group in working towards solutions, for example, the Herpes Group, SHADO, Depressives Anonymous and all the womens' health groups.

Interactions. All the groups concerned with a specific disease or condition, with the exception of the Herpes Group, aimed to educate health professionals about the personal and social dimensions of coping with the particular disease or condition. A few set out to challenge professional control and expertise, and many sought to improve professional sensitivity to the human dimension of the complaint and its sequelae. The Herpes Group challenged the professional control of both the diagnosis and treatment of genital herpes.

With two exceptions (the Herpes Group and Depressives Anonymous), all the groups aiming to challenge professional control over health care planning and delivery were city or locally based groups concerned with general problems or health issues. Women's health and maternity information groups were particularly concerned to de-mystify and de-medicalize conditions which they saw as natural physiological processes. In addition, groups in working class areas, often ill-served by the statutory services, were working to improve public access to and control over health information and services.

Discussion

This study has shown that in a specific locality, self-help groups are providing services which overlap with, complement and sometimes challenge statutory health care provision. They constitute an important element in 'community participation in health care', a major objective of the World Health Organization's strategy of 'health for all by the year 2000'.[12] However, this objective raises important questions, not just about the rate of progress or the scale of non-professional involvement in health care, but also about the reactions of professionals to this trend. Medical education is still failing to prepare doctors for inter-professional teamwork let alone for the more problematic area of community participation in health care.[13] Undoubtedly, the hostility towards the medical profession exhibited by a handful of community groups in this study reflects arrogance by some doctors towards the problems of these sufferers.

It might be expected that, as a community-based discipline, general practice would be in the vanguard of progress towards community participation, especially when its role in the continuing care of chronic illness and its links with community networks are considered. It is clear from this study that many self-help groups address needs unmet by the statutory health and social services. General practitioners could play a major role in referring people to such groups, and in facilitating the access of groups to resources. The finding that the majority of groups seek closer links with primary care, suggests that general practice is either unaware of the scale of the informal health movement, or has failed to negotiate an effective working relationship.

In any locality, progress towards such a working relationship is likely to pass through several stages. First, the primary health care team needs to become aware of established groups and their role in health care. Secondly, use of the group's services by appropriate referral of patients will encourage those groups with objectives which are shared by general practice. Sometimes general practice may be able to help a group directly, by providing premises in which to meet, or professional and administrative support. More often it will be through the referral of a patient who, while seeking help, lends momentum to the group's activities. Rarely, by identifying unmet need in a patient the general practitioner may be instrumental in the creation of a new group. Thirdly, representatives of general practice, logically local medical committees, could meet regularly with representatives of the self-help movement in order to monitor the relationship.

Two types of self-help group will present particular challenges: those hostile to medicine may come into open conflict with general practice and those seeking improved services may take on a party political flavour. However, groups of these types represent a minority of the self-help movement and most general practitioners will understand the origins of such hostility, and be able to work alongside those who exercise their democratic rights in the cause of health.

Overall, self-help groups show an impressive diversity and energy and represent an important resource for primary health care which general practitioners could help promote and sustain.

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