WORLD HEALTH ORGANIZATION
REGIONAL OFFICE FOR EUROPE

WELTGESUNDHEITSORGANISATION
REGIONALBÜRO FÜR EUROPA

ORGANISATION MONDIALE DE LA SANTÉ
BUREAU RÉGIONAL DE L'EUROPE

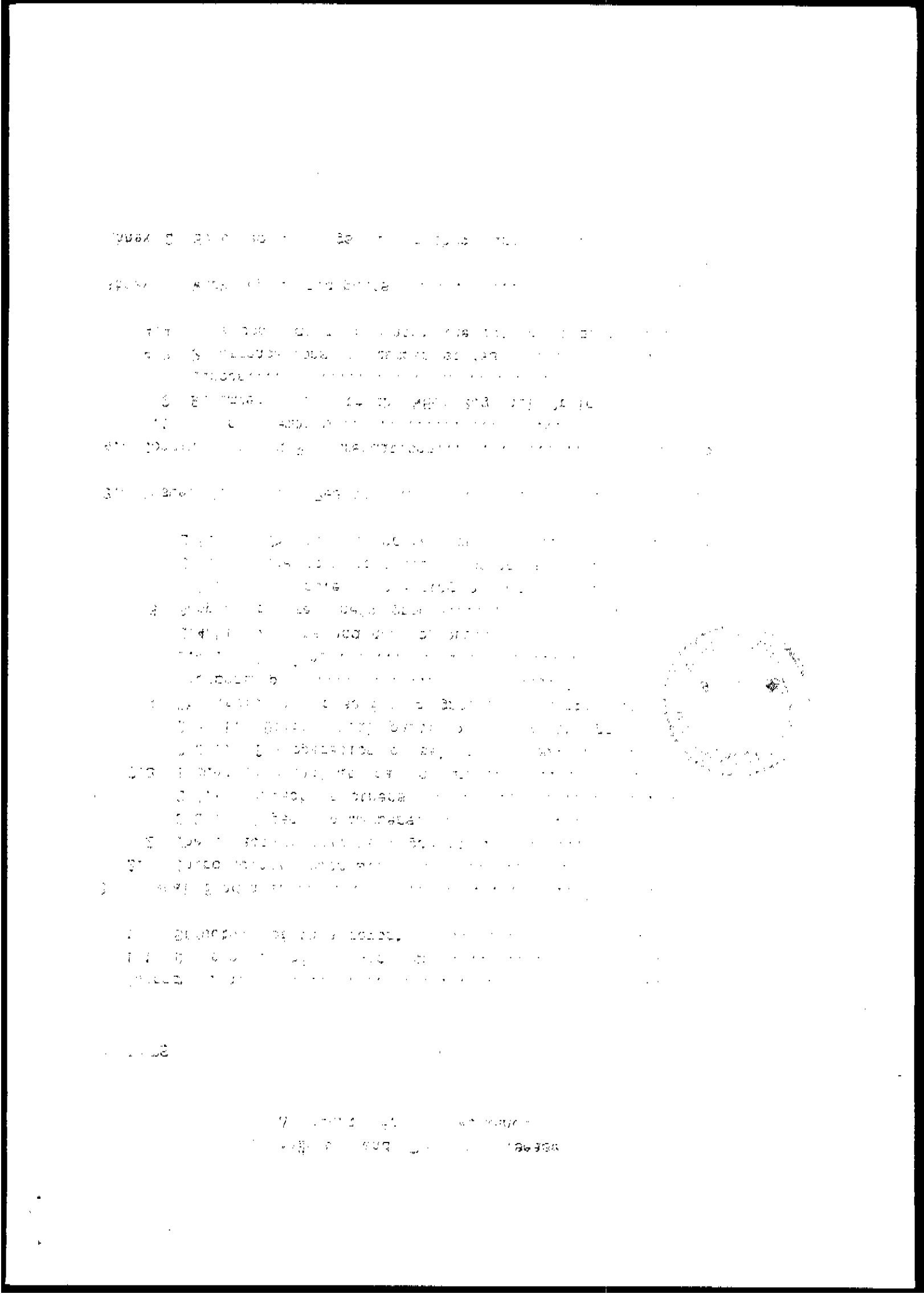
ВСЕМИРНАЯ ОРГАНИЗАЦИЯ ЗДРАВООХРАНЕНИЯ
ЕВРОПЕЙСКОЕ РЕГИОНАЛЬНОЕ БЮРО

SELF-HELP AND CHRONIC DISEASE

Report on a workshop

Leuven, Belgium
28-30 January 1987

ICP/PHC 318
UNEDITED
ENGLISH ONLY
LIMITED DISTRIBUTION



Self-Help and Chronic Disease
A Report from a Workshop

CONTENTS

Self-Help and Chronic Disease
A Report from a Workshop

Leuven, Belgium
28-30 January 1987

1. INTRODUCTION

1.1 Description of the workshop

This workshop was organised by the International Information Centre on Self-Help and Health, on behalf of the World Health Organization's Regional Office for Europe. It took place in Leuven, Belgium over two and a half days, 28-30 January 1987. The workshop should be seen as one further development in the WHO's strategies for attaining 'health for all by the year 2000'. It was set up on the premise that improving primary health care should form a central part of this goal and that collective self-help has a major contribution to make in this area. Self-help is relevant to every aspect of health, including mental and social as well as physical well-being, and can be seen to have a role at every stage - from prevention and health promotion to health care and rehabilitation.

The WHO, particularly the European Region, has taken an active stance with respect to self-help, both in promoting the idea and in stressing the importance of support structures. Through its programme on health education and lifestyles, the Regional Office has provided the impetus and support for a series of consultations and workshops. These include 'Self-Help and Health' (Copenhagen, December 1980), 'WHO, Self-Help and Health' (Leuven, November 1981), 'Mutual Aid: from Research to Supportive Policy' (Höhr-Grenzhausen, June 1982) and 'Supporting Self-Help' (Leuven, January 1986) and they recommended a number of practical measures, as well as further research in this area.

This workshop, bringing together researchers in this field, was derived from both the recommendations of previous workshops and the work of the International Information Centre on Self-Help and Health. The selection of participants and the operation of the workshop reflected the WHO's approach of widespread consultation and dialogue. Its outcome should be judged not only by its conclusions and recommendations but also by the opportunities it afforded for exchange of information and experience and the establishment of new informal contacts and networks.

The workshop was convened on the assumption that the time was now ripe for a review of existing evidence about self-help. A great deal of knowledge has been accumulated about the operation and effectiveness of self-help groups and it is right to begin to distill and disseminate this understanding. At the same time, it is a good time to begin to review and assess the growing policy developments in the field. Bringing together the leading researchers in this field, enabling them to compare their research and analysis, provided an opportunity to test existing views about self-help and its contribution to those with chronic disease. Consideration could also be given to the transferability of conclusions, from one country to another as well as from one disease to another. There was therefore both an academic focus and a practical concern to draw out recommendations.

The participants comprised primarily academic researchers who had completed research relevant to self-help and health. A few worked directly in the field of public health policy or for organisations with a self-help component. A wide range of disciplines were covered by the participants, including medical sociology, social medicine, clinical medicine, social psychology, political science, social administration and social work. Mrs Liliane Trienpont, advisor to Miss Rika Steyaert, Minister for the Family and Social Welfare of the Flemish Government, joined the participants on the first day. Dr Helmut Milz, consultant for the Unit for Health Education of the Regional Office for Europe of the World Health Organization, represented the Regional Office and welcomed the participants on behalf of Dr Ilona Kickbusch, Regional Officer for Health Education. A complete list of participants is attached in Annex 1.

1.2 The structure of this report

This report describes and summarises the conclusions reached by researchers in the workshop. It is intended to stimulate discussion within the WHO and to make specific recommendations. A number of distinct topics were covered by the workshop and these are discussed in a section on general findings. These include the impact of self-help groups, issues of organisational dynamics, the incidence of groups and differential participation, and support for self-help. In the course of these discussions, some gaps in existing knowledge were identified and issues deserving further exploration noted. These are examined briefly in a separate section on issues for further research. Finally, the implications for WHO policy, and for policies of its member states, were considered in some detail and a

separate section on conclusions and recommendations is provided below.

In the interest of brevity, this is not a verbatim report on the workshop and individual contributions are not cited separately. Similarly, individual studies and publications are also not cited in the text. It might be noted that the participants' research covered self-help in the context of many differing chronic diseases and handicaps, including diabetes, rheumatism, chronic skin disease, cancer, sarcoidosis, hypertension, blood diseases, huntington's disease, mental handicap and others. A list the principal writings of the researchers present, showing the publications from which their conclusions were derived, is provided in Annex 2.

2. GENERAL FINDINGS

2.1 Introductory remarks

Self-help groups are no longer uncharted territory. For many years, there had been widespread professional awareness of their development in Europe and America but little systematic knowledge about their operation or effectiveness. The presence at the workshop of so many researchers, from disparate disciplines and environments, demonstrated the wealth of knowledge now available about self-help groups and chronic disease. It was found that there was a great deal on which the researchers could agree; there are increasingly secure foundations on which to build conclusions and draw recommendations.

Self-help groups are essentially groups of people who feel they have a common problem and have come together in order to do something about it. Although the question of definitions was not explored by the workshop, several definitional issues were identified. First, some groups are strictly local, while others form part of a national organisation. The workshop focussed on issues surrounding the local (primary) group, regardless of its affiliation to a wider body. Second, there was consensus on the need to distinguish different functions and audiences of groups. On the one hand, they are concerned with the social and health needs of their members (called by some 'defensive' functions), while on the other, they are concerned with the broader policies for and provision of health care (termed 'offensive' functions). These may or may not be combined within any one individual group. Third, it was agreed that self-help groups should be seen as one vehicle for health promotion, carried out by

key individuals who have come to terms with their own disease.

One of the key elements of self-help is its holistic approach to individuals and their problems. A person is viewed not solely as someone with a particular disease, which needs treatment, but as an individual with a need for a wide range of kinds of care and attention. This approach is not unique to the self-help context, but it is well-demonstrated through it. There are important lessons to be learned from such a perspective.

Self-help groups can be seen to be particularly appropriate in the context of chronic - as opposed to acute - diseases. Chronic disease, by its very nature, creates a new and permanent 'state of being'. Sufferers must learn to cope not only with a new set of symptoms but also with a new sense of identity. They may also need to make substantial changes in their day-to-day lifestyles and living conditions. Self-help groups provide patients an opportunity to meet and learn from one another over time, both about how to detect and control symptoms and about how to come to terms with their new situation. Patients who have had a disease for some time can provide a useful model for those who are new to it, offering a reassurance that it is possible to live with - and cope with - the condition.

The development of self-help groups presents a kind of conundrum for those concerned with public policy. On the one hand, they can be viewed as solely 'private' bodies: groups of people who find their mutual company congenial and derive a sense of benefit from taking part (as with a group of friends or a sporting club). On the other, they can be viewed as having an additional 'public' function: a contribution to the health status of the population (as with programmes for health education). To the extent that they are viewed as the former, they are a matter solely for the individuals involved. In contrast, to the extent that they are viewed as the latter, they are a matter for social policy. The growth of attention to these bodies, from national governments as well as from the WHO itself, suggests that the broader social interpretation is gaining currency.

2.2 The impact of self-help groups

Probably the most central issue underlying any discussion of self-help groups is their impact. Are these groups helpful and, if so, in what ways and under what conditions? Two separate kinds of impact were identified: on their individual members and, more

widely, on the political and social environment in which they work. These are discussed in turn.

2.2.1. Impact on members. From their research findings, the workshop participants were agreed that self-help groups can have a substantial and beneficial impact on people with chronic disease. Across many countries, and across many different conditions, they provide an important source of social and emotional support to those who belong. They help to raise members' sense of identity and to overcome loneliness and isolation through shared social activities. For some members, participation plays a critical role in enabling them to come to terms with and accept the nature of their condition. For some, too, there is a growth of 'empowerment', with an improved capacity to look after their own health and promote the health of others.

At the same time, self-help groups are an important source of information and advice, both about coping directly with the particular disease and about other sources of help. They increase members' awareness of both the quantity and quality of external help and therefore their ability to exercise informed choice. Some self-help groups also provide various kinds of services to their members, from small casual exchanges (such as babysitting) to more substantial means of helping people with their condition (such as care centres for people with the disease or specialised counselling arrangements). These may differ from equivalent 'mainstream' services in content and style, but they also may be taken over by other service providers in their area.

But not all effects of self-help groups are positive. Some groups were also found to have a negative impact on members. While creating a bond between members themselves, some groups isolated members from non-members or indeed the wider community. A tendency to create a high level of expectation among members, not always capable of being fulfilled, was also noted. It had also been found that discussions within a group setting could seem 'academic' or unrealistic, so that suggestions were not followed up when the person was at home. In some cases, there is also a tendency to develop a single factor etiology with respect to a condition, leading to an inappropriately narrow approach to particular problems.

Research evidence on the physiological or psychological impact of self-help groups on members is limited and possibly conflicting. There are some data to suggest positive changes in some physiological indicators (for instance, for hypertensives and diabetics) and a positive impact on capacities for self-healing and self-

reliance, arising from participation. There has been little research, however, on the effect of involvement in reducing personal stress.

What is certain is that one must be cautious not to generalise too freely about the impact of groups on members. This differs enormously according to the nature of the condition for which a group is formed. Benefits from involvement also differ according to the stage in the disease at which a member takes part. They also vary with the degree of stigma attached to the condition.

2.2.ii. Impact on others. But many groups extend their focus beyond their immediate members to seek to engender greater public awareness about their condition in particular and health needs in general. In some cases, this is a matter of de-mystifying the problem; in others, it is more a matter of gaining public (or private) resources to bring to bear on the condition. The 'advocacy' role is an important one for many groups. Similarly, some are concerned to raise funds for further research into prevention or cure.

Some interesting issues arise with respect to the impact of self-help groups on health professionals. It was argued that through involvement in a group, such professionals often become considerably more knowledgeable not only about the group itself but also about the condition around which it was formed. They also learn a great deal about patients' problems and views. In addition, professionals often come to realise that self-help is a useful means of solving problems and is not a threat to themselves. It was felt that there may be an increasing sympathy among professionals with respect to self-help in some areas. On the other hand, there is a danger that very successful groups may antagonise professionals, in part by obtaining public resources at the expense of broader activities for health promotion. Some professionals were thought to view self-help groups inappropriately as a substitute for their care.

Self-help groups, it was noted, mobilise new resources into the provision of health care. A new kind of 'volunteer' can be seen to emerge within groups, providing help to others with the particular disease or condition. In some areas, they also lead to new ways of perceiving needs for care and organising around them. Focussing clearly on one condition, strict professional and institutional boundaries tend to be ignored. There is a concern to integrate services around their condition, forming new coalitions of interested lay and professional people. This tendency is not evident in all countries, however.

The long-term impact of self-help groups on society at large was an issue of some interest. Actual evidence is modest. It would be exceedingly difficult to trace, as a long time span is necessary and cultural changes are in any case highly subtle. Similarly, the impact of self-help groups on broader attitudes to health is interesting, but difficult to assess. Some caution was urged in making claims here. Such impact undoubtedly varies notably from one country to another, affected both by particular health care arrangements and by local cultural norms. Attention was called to the potential significance of systems requiring medical professionals to compete for patients, providing them an incentive to seek new ways of attracting patients to their care.

2.3 Issues of organisational dynamics

The workshop participants had found in their respective research that self-help groups do not all function in the same way. There are substantial variations in the nature of the structures and activities of groups as well as in the extent to which they gain member involvement. Indeed, there is substantial variation in groups' longevity. A number of issues concerning organisational dynamics deserve exploration.

2.3.i. The operation of self-help groups. It was widely agreed that the concept of 'reciprocity' underlies the development of self-help groups, emphasised by the fact that they are also known as 'mutual aid' organisations. But it is clear that actual reciprocity is uneven, both within individual groups and across groups as a whole. There is a need to question the extent to which an exact reciprocity among members is essential and to examine the nature of the processes involved. 'Serial reciprocity', whereby help received is paid back to others over time, may be one way in which groups retain a reciprocal element. Service provision by some members to others, including non-members, clearly undercuts the rhetoric of reciprocity. This may not be important either to givers or to receivers, but raises interesting questions about its distinctness from professional relationships.

The goals and functions of self-help groups tend to change over time, it was noted, in response to perceived changes in needs or expectations. There is a tendency for some new groups to concentrate on issues surrounding the somatic aspects of their condition and then to broaden to a wider health-improving focus. Groups also change in response to changing concerns of members; the interests of older members, for instance, are often quite different from younger

ones. New members commonly bring a particular perspective. There may be a critical time for some groups, particularly long-standing ones, when they become isolated and moribund. It was suggested that some groups have what might be judged a 'natural' life span.

The participants pointed out that the organisational dynamics within a group is affected by the nature of the problem around which it is formed. Some conditions affect a more heterogeneous population than others; some endure over longer periods or change their impact on sufferers over time. Some organisations attempt to accommodate varying interests within them by developing sub-groups within the larger whole. The role of any national body may prove crucial, facilitating the development and success of local groups. Organisational dynamics may also be affected by broader external factors, such as the political and professional climate. The importance of the cultural context must not be underrated.

2.3.11. Differential participation within groups. A number of issues surrounding different levels of involvement were explored. It was commonly found that people do not all want to be active in the same way. Some want to be highly active, some want to attend meetings but keep in the background and some simply want to know the group 'is there'. The problem of group leadership is clearly a central one. Some groups are formed by one strong, sometimes charismatic, leader, who plays a key role in generating an enthusiastic membership. Other groups seem to be formed almost accidentally, with their 'leaders' in no way prepared for their tasks and role. In both cases, questions arise about the impact of the leader on the subsequent development of the group.

There are also issues concerning group maintenance and the retention of leadership skills. It has been found that in some groups, where new members are not encouraged, a small clique of actively involved people develops. In this case, as well as in others, group leaders are likely to stay too long in their job. This has been found to be unhealthy for the group and tiring for the leaders. It was suggested that some leaders experience 'burn-out', in much the same way as over-worked professionals. On the other hand, a constant turnover of leaders can also be difficult for a group. In such cases, there is no pool of leadership experience on which to draw.

Some discussion focussed on the meaning of 'participation' in a group. In general, a feeling of involvement in a group can be engendered within the group as a whole or between members on a one-to-one basis. There is also a question of what is meant by 'active' participation. Naturally reserved people, for instance, may not

play a highly visible role, yet may feel fully involved. This may also be the case where there are language problems or other difficulties in intra-group communication.

2.4 The incidence of self-help groups and differential membership

In considering the effect of self-help groups, it is necessary to pay some attention to the extent of opportunities to take part in them. How widespread are they and what sorts of conditions are covered by them? What affects the disposition of people to become members and take part? The workshop also discussed these issues.

2.4.i. Incidence. It is evident that not every chronic condition is equally well served by self-help groups. Yet the nature of the conditions covered seems to vary considerably across national boundaries, with some interesting contrasts noted. Most workshop participants found it difficult to specify which chronic diseases were not covered by self-help groups in their country, although they felt that there was unequal coverage.

Differential incidence relates to variations in both the birth rates and the survival rates of groups. Both depend in part on different national traditions, as well as the socio-economic and political environment. There are also more obvious factors, however, such as the prevalence of a disease and its significance for members. The importance of alternative support systems must also not be overlooked. Issues surrounding organisational maintenance are also crucial here, as they affect the longevity of groups; these include finding leaders with the 'right' personality and skills, gaining referrals from key local professionals and having some system for group support.

The incidence of groups also varies notably within individual countries. This is equally pertinent to potential members, who cannot take part in groups located well outside their own immediate area. It was generally agreed that, whatever the national coverage of particular diseases, local coverage was very patchy indeed. Questions were also raised about the 'openness' of groups to new members. The potential role of national organisations in developing local groups, or creating conditions favourable to their emergence, was noted. Similarly, local clearing houses can play a key role here, providing practical advice and information.

2.4.ii. Joiners and non-joiners. Related to the question of incidence and coverage is the question of who takes part in self-help groups. Is non-participation a function of real choice or does it arise simply from lack of an appropriate group or lack of knowledge about a group's existence? There is considerable research evidence that those who take part vary systematically from those who do not. There is a tendency for 'joiners' to be middle class, educated, female, elderly and not from ethnic minority populations or rural areas, although of course this varies somewhat according to the nature of the particular problem. They also tend to be 'socially competent', having both experience of expressing their needs and a sense of confidence in their ability to solve problems themselves.

It might be added here that not all joiners are direct sufferers of a disease; in many cases, it is the relatives who join a group and in others well-wishers, who want to provide support. In addition, if one looks at the membership of groups over time, it can be seen that there are variations in the duration of membership, arising in part from the duration of the condition itself. With some conditions, it has been found that people who had the disease or problem choose to remain active in a group, although they are no longer directly suffering from it. Indeed, such people are often some of the more active members of groups.

Some evidence about members' motivations to join was also put forward. Those who join tend to seek information about their condition, to overcome feelings of uncertainty. Many are simply lonely. On being faced with a new disease, people tend to follow their normal coping strategy; if this involves 'talking through the problem' then they are more likely to join a self-help group. Some people seem to seek out others in a position similar to their own. There is also a question of relative needs for help and the alternative help available. It was noted, however, that understanding the motivations of those who join provides a necessary but not a sufficient explanation of differential participation.

Many 'obstacles to joining' were noted. First and foremost is lack of knowledge that a group exists. In addition, however, there can be practical problems in getting to a group, such as transport, finance or finding a babysitter. It is obvious that many of the conditions for which groups are formed themselves create hindrances to attendance, for instance, lack of mobility. In addition, it has been found that some potential members are dissuaded from involvement by a spouse or other significant person. People living in small close-knit communities may fear the loss of their anonymity.

Problems may also be experienced by people who see themselves as minorities, whether in terms of age, sex, ethnic origin or some other characteristic, and fear they will not feel welcome. Some people also lack any cultural norm favourable to a self-help approach. Incentives to join are likely to be lower where other primary social networks exist. Some people also simply lack the time to get involved.

The issue of differential membership is a complex one. To the extent that it reflects unequal access to information about the existence and benefits of groups, it is a matter for some public attention. To the extent that it is a reflection of differing personalities and tastes, it should be little cause of concern. Ultimately, the workshop participants agreed, there is a need to accept that self-help is not a universal solution and that many people, with full knowledge and competence, do not choose to become involved in groups.

2.5 Support for self-help groups

The issue of how best to provide support to self-help groups is very live in many countries. Given the particular difficulties which self-help groups can experience, combined with differential participation in them, some support may help groups to keep going and to acquire new members. It may also serve to equalise access to groups, for instance among minority populations who may be less familiar with the existence of a group. A number of different systems have been tried, both nationally and locally; these include both specialist (focussed on one particular organisation or problem) and generalist (open to anyone) systems. The most common form of the latter is the clearing house or support centre. There is also growing interest in encouraging local health professionals to take a lead in this regard.

2.5.1. <u>The role of clearing houses</u>. There has been a substantial growth in the number of self-help clearing houses in Europe over recent years, particularly in Germany and in Britain. These can be both national and local. They serve in part as a channel for information about the location of self-help groups, responding to inquiries from ordinary people anxious to find a particular group. They also serve, however, as a focus for support to self-help in their area. They provide practical advice about publicity or premises and, in some cases, broader kinds of support to leaders or potential founders of self-help groups. They can be quite helpful in getting groups off the ground. They can also serve as a stimulus

to others, such as local professionals, to provide help to groups. In addition, and not unimportantly, they provide a symbol of public interest in self-help.

2.5.ii. The role of national organsations. The contribution of national bodies to the support of local groups (often called 'branches' or 'chapters') was noted, but not heavily explored. These have an advantage over generalist support systems in having greater familiarity with the problem around which their groups are formed. Those involved at national level may, indeed, have emerged from involvement at local level, providing them particular understanding of local needs. National organisations can also play a key role in influencing the climate of opinion in which local groups operate. In some countries, governments have provided financial support to national specialist bodies to assist them in their role. Some research has shown that specialist community work can play a key role in increasing participation in groups and the promotion of new groups. On the other hand, it was found that in some cases the centre can get out of touch with and unrepresentative of the local group.

2.5.iii. The role of professionals. Workshop participants were generally agreed that the role of professionals in working with self-help groups is a sensitive one. Group members are often deferential to professionals, conflicting with the self-help ethos of egality. At the same time, professionals often call attention to their presence in the group, even unintentionally. Some concern was expressed that professionals sometimes try use groups to pursue their own particular aims.

A number of specific ways in which professionals can help groups were noted, for instance, assistance with grant applications and offering the use of their premises. In some cases, it was suggested that professionals might concentrate on removing obstacles to participation (for instance, by referring members), rather than actively seeking ways of providing help or facilities. Certainly, it was felt that referring people to groups was a key issue; patients tended to be reluctant even to try out a group if such activity had to be undertaken 'behind the doctor's back'.

It was agreed that there was a need for the development of skills in self-help support, viewed as a particularly specialised form of community work, for workers in this field. One key element here is avoiding the creation of dependency. In some cases, this might mean a certain degree of de-qualification; it was suggested that professionals would need to see themselves as 'professional non-

professionals'. Health professionals generally could also use some introduction to and training in self-help. For instance, they may need to learn not to stress the traditional patient role. Reverse role-playing within groups can help professionals see issues from the patient's point of view as well as vice versa. Some professionals had been found to be reluctant to get involved in groups because they feared their own services and capabilities would be discussed.

Underlying the discussion on support to self-help was a concern that self-help groups be enabled to retain their individuality and dignity. They should have a central role in choosing if they want help and of what kind. Their interests will not be best served where central organisers, even with the best of intentions, seek to make decisions on their behalf. Caution should be exercised by those in authority that there is not too much regulation or expectation of regularity. On the other hand, this is not a legitimate reason not to provide any support for self-help.

3. ISSUES FOR FUTURE RESEARCH

There was widespread agreement among the workshop participants that evidence concerning the impact of self-help groups, while growing, needs to be extended. Not surprisingly, there was a concern to generate new data. It was argued that there is a need for studies focussing on both the psycho-social and medical effects of self-help groups on members and the longer-term wider social impact. These need to have a long time-scale and a broad brush; groups may affect members' families, their local community, their wider medical system and, more fundamentally, their culture.

A number of issues concerning the impact of self-help groups were raised. There is a need to develop more sensitive research tools to capture the subjective components at play in this area. While the relative merits and costs of self-help groups against other methods of intervention would be exceedingly difficult to assess, there is a need to begin to ask questions about the quality of services provided by self-help groups. Can it be stated clearly, as is expected in the case of professional services, that they - as a minimum - 'do no harm'? Impact studies should be careful in setting criteria for evaluation. Underlying these questions is a concern to understand which groups are served best by self-help groups and, conversely, those for whom groups may be inappropriate.

There was considerable interest in developing research on the impact of self-help groups on medical professionals and the services they provide, as well as vice versa. When they become directly involved with groups, do local health professionals begin to incorporate new ideas into their own provision of care? On the other side of the coin, is there a tendency for them to 'capture' groups and use them for their own purposes?

Questions concerning members and the nature of their involvement were also seen to deserve further exploration. Who are the joiners of self-help groups and what proportion do they form of potential membership? What importance should be placed on differing levels of participation? What are the characteristics of those who do not take part? A study of people inquiring at clearing houses might be interesting, to discover the numbers and nature of those who join and become active, those who become inactive members and those who never join at all.

Issues surrounding the economic impact and significance of self-help groups were also raised, viewed as one part of an economic evaluation of the lay health care sector. What resources are created and affected by the development of self-help groups? On a wider societal level, some interest was expressed in trying to explain the phenomenal growth of self-help groups in Europe, America and, indeed, elsewhere. It was suggested that comparative studies might prove useful, drawing out cross-cultural differences with respect to self-help.

Accompanying the concern to generate more data was a complementary concern for more theory and explanation. This entails studies which not only demonstrate outcomes but also begin to analyse the nature of the conditions which give rise to varying effects. To what extent are differential outcomes the result of political and social factors intrinsic to a particular environment? Under what circumstances do self-help groups become successful pressure groups? Under what conditions do they have a notable impact on members' sense of empowerment and independence from the medical profession? What is the impact of different levels of involvement on impact outcomes? There is a sizeable literature on small group behaviour, yet little attention has been given to its pertinence to the self-help group context. It would be interesting to marry this theoretical perspective to the particular intervention and theapeutic aspects of self-help groups.

Some researchers were concerned to develop studies which could prove useful to groups themselves and to ensure the feedback of the

results to the groups. Questions of sponsorship might arise here, although some organisations might wish to support some small-scale research themselves. What helps groups to become more successful in achieving their aims? How are the techniques of self-help diffused between groups or within individual groups? On a more practical plane, how long should groups continue to meet and how frequently? How can new members best be accommodated within an existing group? What is the role of national organisations with respect to local groups affiliated to them? On the other hand, concern was expressed that groups should be viewed as having an independent (and non-public) life; researchers should be careful not to be intrusive and refrain from a tendency to be directive.

4. CONCLUSIONS AND RECOMMENDATIONS

4.1 General remarks

The conclusions of this workshop are not largely new. Most can be found in one place or another within the growing literature about self-help and chronic disease. Many have been stated or implied in the recommendations of earlier workshops in this field. The particular contribution of this workshop is a bringing together of ideas and issues from studies carried out in many different countries, crystallising their implications for policy and practice. It remains here to spell these out for the Regional Office for Europe of the WHO itself and for its individual member states.

Very broadly, the conclusions of the workshop were positive but cautious. Self-help groups have a great deal to offer their individual members and can also have a beneficial impact on the wider society in which they function. They represent an important contribution to the promotion of individual health care and bring to discussions a refreshing 'lay' view of patient care. Self-help groups can also be described as 'efficient' bodies, inasmuch as they carry out a number of different functions at the same time. Their holistic approach to individuals merits particular attention, especially among those who have tended to follow a more limited clinical model. They represent and encourage a wider view of health as a <u>social</u> idea.

But self-help groups do not function without problems and it would be inappropriate to place too high expectations upon them. They are not universally available, in terms either of every disease or of every country or local area. Not everyone, in any case, finds them

an appropriate solution to his or her particular needs for care. They should be viewed as an important complement to existing systems of health and social care and in no way a substitute for them. Their contribution needs to be recognised but not exaggerated. In particular, there remain a number of unanswered questions about the significance of self-help, both to those who belong and to those who do not.

A number of recommendations were put forward, as decribed below. These concern, first, the World Health Organization, Regional Office for Europe, and, second, individual member states.

4.2 Recommendations to the World Health Organization: Regional Office for Europe

The WHO is currently well attuned to the need for health promotion. The contribution of self-help groups to this goal needs to be recognised and applauded. To a large extent, of course, the WHO is already active in this area: it provides support for the International Information Centre on Self-help and Health, it has supported a number of workshops on the subject and has taken note of self-help in some programmes. But it could nonetheless do more. It is not a matter of devising complex new programmes, but of becoming even more sensitive to the potential role of self-help groups, as one of a number of non-professional resources, in the delivery of health care. The issues arising should be seen in parallel to those raised by professional medical manpower.

The overriding response of the WHO to the development of self-help groups should be one of facilitating and enabling them to flourish in their respective countries and localities. Self-help groups, it has been found, are indigenous to most countries. But they are also a local phenomenon, and cannot readily be imposed from outside. The potential facilitating role should, however, not be undervalued. It is particularly critical at this time because of the disproportionate attention which has been given to professional elements in the health care system. There is a need to right the balance in favour of the consumer of health care.

In addition, there is an issue of equity - or equal access to resources. As self-help groups have been found to provide members a valuable source of care and support, and some have themselves become channels for some public resources, it is essential that a real effort is made to ensure equality between members and potential members. Through promoting attention to groups, encouraging their

development and individual participation in them, the WHO can and should play a key role in affecting equality of access to groups.

The role of the International Information Centre on Self-Help and Health in promoting self-help needs no underlining. Its newsletter is widely read and its service in providing a network, both for researchers and for those concerned with policy, is highly valuable. In addition, its contribution to the organisation of workshops on self-help, including the present one, is important. These all serve to keep the needs of self-help on an international agenda. Continuing support for the Centre should be an essential part of the WHO programme for health education and health promotion.

Finally, the workshop participants recommended that the WHO should seek to establish a means of calling attention to examples of good practice in self-help and self-help support within individual member states. The WHO was urged to give some early attention to how this could best be achieved. It would enable good ideas to be disseminated and lessons to be learned. The importance of collating and building on existing knowledge cannot be over-stressed; it would be a pity to lose the wisdom which has been developed, often both expensively and painfully, over time. A WHO-sponsored self-help advisor, who would keep in touch with developments within the member states, was one idea put forward toward this end.

4.3 Recommendations to member states

The WHO is requested to bring to the attention of the member states some additional recommendations, as follows.

National governments, like the WHO itself, should give priority to ways of facilitating and enabling self-help groups to flourish. Again, their role here is inevitably limited by the very local character of self-help. Yet governments can and should give due recognition to the value of self-help for coping with chronic disease and this should be reflected in policies and programmes for self-help support. They should seek ways of strengthening local communities to mobilise their own resources. Indeed, this should be part of a wider look at their capacity to respond to the broad lay health care sector. Furthermore, the important role played by national self-help organisations should be acknowledged and furthered.

The workshop participants cited a number of ways in which national (and regional and local) governments should seek to affect self-help

groups directly. The establishment of - or provision of financial support to - clearing houses or support centres, for instance, would prove particularly fruitful. In addition, programmes should be set in motion to provide direct funding to self-help groups. Similarly, programmes should be set up to provide training for professionals on how to work with groups, as well as for group members themselves. Greater attention should be given to self-help in the education of key health professionals, particularly general practitioners and others involved in primary health care. This can help substantially in developing an awareness among doctors (and others) of the significance of self-help, from an early stage in their careers.

Various methods of disseminating information about self-help should also be encouraged, for instance directories of self-help groups. Clearing houses often play an important role in the creation and distribution of such directories. Ways of furthering a 'networking' function, identifying and bringing together people with similar functions working in different areas, should be explored. These may include leaders of individual groups, local professionals with a particular interest in self-help or those employed specifically to work with self-help groups. They need to be given opportunities to learn from one another. These and related issues were explored in greater depth in an earlier workshop*.

There is also an important question about the role of self-help groups in the wider political system. Those responsible for developing policies should seek to involve self-help groups in key stages of policy and planning. Where there are committees to consider health issues or the social care of people with specific diseases, for example, representatives of relevant groups should be invited to take part. There is, of course, a limit to the number of groups which can be so involved, but there is a strong case for some representation. Groups have accumulated considerable knowledge and there is a lot which can be learned from them.

Alongside these positive recommendations, the workshop participants were anxious to ensure that self-help did not come to be seen as in any way a substitute for professional care. Any programmes in this area should respect the unique contribution groups can make, but not place on groups - or, indeed, on the wider lay health care sector - expectations which they could not fulfill. Furthermore, supporting self-help should not be seen as a means of saving public expenditure, as groups do not and cannot replace publicly-provided

---

* See WHO: Euro, 'Supporting Self-Help', 22-24 January 1986, Report no ICP/PHC 114.

services.

Finally, as indicated above, there is a need for additional research on self-help. Some governments have already sponsored studies and such support should be encouraged. Research can play an important function in highlighting the strengths and limitations of groups, enabling both governmental and other bodies to establish appropriate bases for support to them. Research also serves to keep the role of self-help on the public agenda, while confronting the prevalent rhetoric with some analysis and understanding.

4.4 Some concluding comments: the future of self-help

These recommendations have been put forward with a firm eye on the current context. It seemed only sensible to take a hard and practical look at the circumstances and needs of existing groups. But it is also not inappropriate to cast a cautious look into the immediate future. In what ways will self-help groups seem different in five or ten years' time?

Crystal ball gazing is a notoriously hazardous activity; firm predictions are all too frequently knocked aside by subsequent unforeseen developments. In the self-help context, it is likely, however, that in many respects groups will be very much the same over the next decade or so. New groups will emerge and some existing groups strengthened. Some groups may also go into decline. This has always been so. With the growth of clearing houses and support from professionals, however, the self-help phenomenon is likely to become more secure.

But there are also new kinds of groups potentially on the horizon. These are non-disease-specific groups for health promotion. With growing interest everywhere in extending the role of lay people in health care, and growing concern to learn about health in its broadest sense, such groups are likely to flourish. A number already exist in various countries, focussed on broad patient care or participation. They both reflect and foster an important 'holistic' approach to health. Self-help groups themselves, as they begin to talk with one another and learn from each other, may help to spur this development. There are a number of general health issues likely to be born from coalitions, thriving on the search for a common cause.

The effect of such new groups, combined with those of longer duration, will merit close attention. They too may have a positive

impact on those who take part, liberating and extending their ability to promote their own health and that of others. They too may have an empowering function. Perhaps more significantly, they may affect broader service provision, reorienting health services in the direction of more general health promotion. They may serve to place health issues firmly in the lap of public policy, removing them from the more restricted domain of the medical profession.

The concept of a self-help sector, in the final analysis, is a social construct, arising not so much from groups themselves as from outsiders concerned to analyse their role. The principal concern of individual groups is their particular disease or condition and those who suffer from it, now or in the future. They are not concerned with a 'policy for self-help', but only with policies which affect themselves as groups or their individual members. It is outsiders who have recognised their common working form and their common contribution. It has also been left to outsiders, by and large, to argue the case for their generic recognition.

In conclusion, the time is now right for a reiteration of basic principles. The role of the lay person in coping with a chronic disease, and the role of groups of lay people - self-help groups - in this regard, should be stressed and promoted. A number of specific ideas have been put forward in this report and they deserve attention. While the excessive rhetoric associated with self-help needs to be tempered with caution, it has placed self-help firmly on the agenda of public discussion and debate. Self-help groups must now be considered and examined with due care and conjoined in the wider movement for health promotion.

Annex 1

Workshop participants

Dr. A. Barath
College of Nursing, Medical School
University of Zagreb
Mlinarska 38
Y-41000 ZAGREB
YUGOSLAVIA
Tel. 00 38 41 275 450
277 757

Mr. M. Bieber
Cancerlink
46 A Pentonville Road
UK-LONDON N1 9HF
UNITED KINGDOM
Tel. 00 44 1 833 2451

Dr. B. van den Borne
I.V.A., Institute for Social Research
Postbus 90153
NL-5000 LE TILBURG
THE NETHERLANDS
Tel. 00 31 13 662 163
662 443

* Dr. J. Branckaerts
International Information Centre on Self-Help and Health
E. Van Evenstraat 2C
B-3000 LEUVEN
BELGIUM
Tel. 00 32 16 283 202
283 158

Dr. M. Bremer Schulte
Institute for Self-Care Research
Boschstraat 45
NL-6211 AT MAASTRICHT
THE NETHERLANDS
Tel. 00 31 43 888 504
215 423

Dr. G. Galea
Department of Health
Health Education Unit
15 Merchants Street
VALETTA
MALTA
Tel. 00 456 231 246

Dr. D. Grünow
Gesamthochschule Kassel
Projektgruppe Verwaltung und Publikum
Postfach 101 380
D-3500 KASSEL
FEDERAL REPUBLIC GERMANY
Tel. 00 49 561 804 3087

Mr. S. Hatch
Westminster Association for Mental Health
526 Harrow Road
UK-LONDON WQ 3QF
UNITED KINGDOM
Tel. 00 44 1 969 2434

Dr. S. Humble
The Volunteer Centre
29 Lower King's Road
UK-BERKHAMSTED HERTS HP4 2AB
UNITED KINGDOM
Tel. 00 44 27 73 311

Dr. J. Lee
City of Toronto, Department of Public Health
City Hall, 6th Floor
East Wing
TORONTO ONTARIO M5H 2N2
CANADA
Tel. 00 1 416 392 7451

Professor L. Levin
Yale University, School of Medicine
60 College Street
NEW HAVEN CONNECTICUT 06150
UNITED STATES OF AMERICA
Tel. 00 1 203 785 2849

* Dr. A. Richardson
Policy Studies Institute
100 Park Village East
UK-LONDON NW1 3SR
UNITED KINGDOM
Tel. 00 44 1 387 2171

Ms. F. Roca
Institut Municipal de la Salut
Servei de Promocio de la Salut
Pl. Lesseps 1
S-08023 BARCELONA
SPAIN
Tel. 00 34 3 218 1800

Mr. P. Saelens
Trefpunt Zelfhulp
E. van Evenstraat 2C
B-3000 LEUVEN
BELGIUM
00 32 16 283 153

Ms. M. Smet
Koning Boudewijnstichting, Programma Welzijnszorg
Brederodestraat 21
B-1000 BRUSSEL
BELGIUM
00 32 2 511 1840

Dr. Z. Sosic
Stampar School of Public Health
University of Zagreb
Medical School
Rockefellerova 4
Y-41000 ZAGREB
YUGOSLAVIA
Tel. 00 38 41 430 333

Professor A. Trojan
Universitätskrankenhaus Eppendorf
Medizinische Soziologie
Martinistrasse 1
D-2000 HAMBURG
FEDERAL REPUBLIC GERMANY
Tel. 0049 40 468 56

Dr. J. Vincent
Centre for Research in Social Policy
Loughborough University
UK-LEICESTER LE11 3TU
UNITED KINGDOM
Tel. 00 44 509 263 171 ext. 660

W.H.O. Consultant:

Dr. H. Milz
World Health Organization
Regional Office for Europe
Unit for Health Education
8, Scherfigsvej
DK-2100 COPENHAGEN Ø
DENMARK
Tel. 00 45 1 290 111

(* = workshop co-organisers)

Annex 2

Selected Writings of Participants

Barath, A.
'Hypertension Clubs in Croatia', in S. Hatch and I. Kickbusch (eds), Self-Help and Health in Europe, W.H.O., Regional Office for Europe, Copenhagen, 1983.

Borne, H. van den,
'Zorg om nazorg', Maandblad Geestelijke Gezondheidszorg, 12, p. 1060-1072, 1981.
Nazorggroepen Kankerpatiënten: Frequentieverdeling van de Onderzoeksvariabelen, Tilburg, Katholieke Hogeschool, 1982.
Zelfhulp bij Kankerpatiënten: de vrijwilliger in de nazorg door de Hodgkin Contactgroep, de Harry Bacon Club, Begeleidingsgroepen voor Borstkanker-patiënten, Tilburg, Katholieke Hogeschool, Studiecentrum voor Sociale Oncologie, 1982.
Achtergrond en betekenissen van lotgenotencontact bij kankerpatiënten, Tilburg, IVA, 1983.
Lotgenotencontact bij kankerpatiënten, Assen, Van Gorcum, 1985.
'Self-help in cancerpatients: a review of studies on the effects of contacts between fellow patients', Patient Eduction and Counselling, 8, p. 367-385, (with J.F. Pruyn and K. van Dam-de Mey), 1986.

Branckaerts, J.
Self-help organisations in Flanders: Summary of the preliminary results of a cross-sectorial analysis based on ten case studies, Leuven, Katholieke Universiteit, Division for Medical Sociology, Belgium.
'Upside down: zelfhulp van Leuven tot elders', Sociaal, 3(10), p. 12-15, 1982.
'Zelfhulp: een inleiding tot het veld en de literatuur', Leren en leven met groepen, 17, p. 5200/1-22, Brussel, C.E.D. Samson, 1983.
'Researching self-help: a social scientist's perspective', in S. Hatch and I. Kickbusch (eds), Self-Help and Health in Europe, W.H.O., Regional Office for Europe, Copenhagen, 1983.
'Birth of the movement: early milestones', in D.L. Pancoast et al.(eds), Rediscovering Self-Help, Sage, Beverly Hills, 1983.
A Directory of Generalised Support Systems for Self-Help in Health and Social Welfare in Europe, the U.S.A. a.e., Leuven, Sociologisch Onderzoeksinstituut, Katholieke Universiteit, 1985.
Zelfhulporganisaties: Literatuuranalyse en explorerend onderzoek in Vlaanderen, Leuven, Katholieke Universiteit, Faculteit der Sociale Wetenschappen, Departement Sociologie, 1985.
'Politics and policies on self-help: notes on the international scene', in S. Humble and J. Unell (eds), The Future of Self-Help in England and West-Germany, publisher under negotation, (with A. Richardson).

Bremer Schulte, M.
From Polarization to Collaboration in Health Care, Interacademiale Werkgroep Werkgroep Ziekenhuiswetenschappen, Maastricht, 1978.
'Groepsbehandeling van psoriasispatiënten volgens de duo-formule', Nederlands Tijdschrift voor Geneeskunde, 126(45), p. 2043-2046, 1982.
'Nazorg hartinfarcten: samenwerking arts-patiënt', Nederlands Tijdschrift voor Geneeskunde, 127(50), p. 2270-2280, 1983.
'Self-help in medical education', in S. Hatch and I. Kickbusch (eds), Self-Help and Health in Europe, W.H.O., Regional Office for Europe, Copenhagen, 1983.

'Patients in partnership with professionals: the duo approach', Education for Health, 1(2), p. 32-37, 1984.
'Medical education in relation to self-activity of patients: strategies for changes', Education for Health, 1(1), p. 33-37, 1984.
'Zelfzorg, een voorwaarde tot het veilig stellen van gezondheid', Medisch Contact, 39(49), p. 1572-1574, 1984.
'Group therapy of psoriasis', Journal of the American Academy of Dermatology, 12, (with others), 1985.
'A survey of lay and professional interest in self-care', Journal of the Royal College of General Practitioners, (with A. Richardson), July 1987.

Grünow, D.
'Formen sozialer Alltäglichkeit: Selbsthilfe in Gesundheitswesen', in B. Badura and C. v. Ferber (eds), Selbsthilfe und Selbstorganisation im Gesundheitswesen, München, Oldenbourg, p. 125-146.
Gesundheitsselbsthilfe im Alltag: Ergebnisse einer repräsentativen Haushaltsbefragung über gesundheitsbezogene Selbsthilfeerfahrungen und Potentiale, Stuttgart, Enke Verlag, (with others), 1983.
'Selbst- und Laienhilfe in der paramedizinische Phase', Allgemeinmedizin, 15, p. 146-151, 1986.
'Why we need data: observations on evaluation research in health-related self-help', in S. Humble and J. Unell (eds), The Future of Self-Help in England and West-Germany, publisher under negotiation (forthcoming).

Hatch, S.
(ed) Mutual Aid and Social and Health Care, ARVAC pamphlet no 1, Bedford Square Press, London, 1980.
(ed) Self-Help and Health in Europe, W.H.O., Regional Office for Europe, Copenhagen, (with I. Kickbusch), 1983.
Self-Help in Practice, University of Sheffield, Joint Unit for Social Services Research, Social Services Monographs: Research in Practice, (with T. Hinton), 1986.

Humble, S.
Voluntary Action in the 1980s, The Volunteer Centre, 1982.
(ed) The Future of Self-Help in England and West-Germany, (with J. Unell), publisher under negotiation.

Levin, L.
'Self-care: an international perspective', Social Policy, 7(2), p. 70-75, 1976.
'Self-care and health planning', Social Policy, 8(3), p. 47-54, 1977.
Self-Care: Lay Initiatives in Health, London, Croom Helm, 1977.
'Forces and issues in the revival of interest in self-care: impetus for redirection in health', Health Education Monographs, 5(2), p. 115-120, 1977.
The Hidden Health Care System: mediating structures and medecine, Bollinger, Cambridge, Mass., 1981.
'Self-care in health: potentials and pitfalls', World Health Forum, 2(2), p. 177-184, W.H.O., 1981.
'Self-care in health', Annual Review of Public Health, no 41, 1983.

Richardson, A.
Self-Help and Social Care: Mutual Aid Organisations in practice, PSI, London, (with M. Goodman), 1983.
Working with Self-Help Groups, London, Bedford Square Press, 1984.
'The diversity of self-help groups', in S. Hatch and I. Kickbusch (eds), Self-Help and Health in Europe, W.H.O., Regional Office for Europe, Copenhagen, 1983.

'English self-help: varied patterns and practices, in D.L. Pancoast et al. (eds), Rediscovering Self-Help, Sage, Beverly Hills, 1983.

Trojan, A.
'Demokratisierung des Gesundheitswesen durch Mitwirkung Betroffener - zu institutionalisierten und selbstorganisierten Formen des Interessenvertretung von Patienten', Forum für Medizin und Gesundheitspolitik, 14, p. 14-33, 1980.
'Lokale Bewegungen, Modelle gemeinderbezogene Gesundheitshilfe in der BRD', Osterreichische Zeitschrift für Politikwissenschaften, 1, p. 93-109, (with J. Behrendt), 1980.
(ed) Gemeindebezogene Gesundheitssicherung, München, (with H. Waller), 1980.
(ed) Sozialpsychiatrische Praxis: Eine Einführung für Medizinische und Psychosoziale Berufe, Wiesbaden, (with H. Waller), 1980.
(ed) Gemeinsam sind wir stärker: Selbsthilfegruppen und Gesundheit; Selbstdarstellungen - Analysen - Forschungsergebnisse, Fischer Taschenbuch Verlag, Frankfurt am Main, (with I. Kickbusch), 1981.
'Groupes de Santé: the users' movement in France', in S. Hatch and I. Kickbusch (eds), Self-Help and Health in Europe, W.H.O., Regional Office for Europe, Copenhagen, 1983.
'Self-help groups and consumer participation: a look at the German health care self-help movement, Journal of Voluntary Action Research, 15(2), (with others), April-June 1986.

Vincent, J.
Constraints on the Stability and Longevity of Self-Help Groups in the Field of Health Care, report to the Department of Health and Social Security, mimeographed, available from the Centre for Research in Social Policy, Loughborough University, 1986.
'The mirror of research', in M. Landau-North and S. Duddy (eds), Self-Help through the Looking Glass, Leicester CVS, Rural Press, (with A. Webb), 1985.
'I don't believe in data', in S. Humble and J. Unell (eds), The Future of Self-Help in England and West-Germany, publisher under negotiation, (forthcoming).

'English self-help: varied patterns and practices, in D.L. Pancoast et al., Rediscovering Self-Help, Sage, Beverly Hills, 1983

Trojan A.
'Lokale Bewegungen, Modelle gemeinde bezogener Gesundheitshilfe in der BRD', Osterreichische Zeitschrift für Politikwissenschaften, 1, p. 93-109, (with J. Behrendt), 1980.
(ed) Gemeindebezogene Gesundheitssicherung, München, (with H. Waller), 1980.
(ed) Sozialpsychiatrische Praxis: Eine Einführung für Medizinische und Psychosoziale Berufe, Wiesbaden, (with H. Waller), 1980.
(ed) Gemeinsam sind wir stärker: Selbsthilfegruppen und Gesundheit: Selbstdarstellungen - Analysen - Forschungsergebnisse, Fischer Taschenbuch Verlag, Frankfurt am Main, (with I. Kickbusch), 1981.
'Groupes de Santé: the users' movement in France', in S. Hatch and I. Kickbusch (eds), Self-Help and Health in Europe, W.H.O., Regional Office for Europe, Copenhagen, 1983.
'Self-help groups and consumer participation: a look at the German health care self-help movement, Journal of Voluntary Action Research, 15(2), (with others), April-June, 1986.
(ed) Wissen ist Macht - Eigenständig durch Selbsthilfe in Gruppen, Fischer Alternativ, Frankfurt am Main, 1986.
Wünsche - Wissen - Widerstand. Selbsthilfegruppen diskutieren mit Politikern und Experten, Sozialwissenschaften und Gesundheit e.V., Hamburg, (with M. Dobler, V. Enkerts, C. Kranich), October 1984.

Vincent, J.
Constraints on the Stability and Longevity of Self-Help Groups in the Field of Health Care, report to the Department of Health and Social Security, mimeographed, available from the Centre for Research in Social Policy, Loughborough University, 1986.
'The mirror of research', in M. Landau-North and S. Duddy (eds), Self-Help through the Looking Glass, Leicester CVS, Rural Press, (with A. Webb), 1985
'I don't believe in data', in S. Humble and J. Unell (eds), The future of Self-Help in England and West-Germany, publisher under negotiation, (forthcoming).