WORLD HEALTH ORGANIZATION
ORGANISATION MONDIALE DE LA SANTÉ

HED/84.1

# HEALTH EDUCATION IN SELF-CARE: POSSIBILITIES AND LIMITATIONS

Health Education Service,
Division of Public Information
and Education for Health

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HED/84.1
English Only



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Report of a Scientific Consultation
Geneva, 21-25 November 1983

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# SCIENTIFIC CONSULTATION ON HEALTH EDUCATION IN SELF-CARE: POSSIBILITIES AND LIMITATIONS - 21-25 NOVEMBER 1983

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## 2. INTRODUCTION

A group of experts in the fields of health education, self-care research and programme development, and health services administration was convened in Geneva to advise WHO regarding the role of education for self-care in the organization's global strategy for health for all. The Director-General, Dr H. Mahler, in his opening address, pointed out that there could hardly be a more resounding justification for the Scientific Consultation on this subject than a statement included in the unanimously adopted Alma-Ata Declaration:

> ...people have the right and duty to participate individually and collectively in the planning and implementation of their health care (36).

There is a long standing interest in this subject, although not labelled "self-care", in the policy and work of WHO. For example, in 1954, an expert committee report on health education discussed helping individuals:

> ...to become competent in and to carry out those activities they must undertake for themselves as individuals, or in small groups, in order to realize fully the state of health defined in the Constitution of the World Health Organization (37).

The goals of the Scientific Consultation and of this report, were to provide to WHO:

1) A summary of the available information relevant to the subject of self-care behaviour;

2) A discussion of the important issues and action areas identified during this working conference; and

3) Recommendations for policy, education, health systems and research directed toward supporting and enhancing effective self-care behaviour in the member states of WHO.

The vital contribution that better self-care behaviour can make to the Member States' goal of Health for All by the Year 2000 is shown by the growing recognition of the importance of individual behaviour to health promotion, disease prevention and care during illness. The health status of an individual (or of a population) is the result of many forces within the individual and the surrounding society. Safe air, water and food supplies as well as adequate nutrition and shelter are prerequisites without which people can do little to maintain their health. Hereditary factors are also important determinants of health status. However, given basic prerequisites, the major determinants of health status are: 1) self-care patterns of daily living; 2) the capacity and opportunity to contain stress and obtain social support; 3) the ability to identify and care for health problems; and 4) the capacity to obtain and interact effectively with appropriate professional services.

In spite of the volume of experiential knowledge and scientific data to illustrate these facts, conflict and debate often surround discussions of self-care. It is important to emphasize that the participants of this meeting do not consider self-care a way to replace doctors, nurses and other workers providing the medical services necessary to cure sick people. In his opening address, the Director-General defined the concept of self-care used as a basis for the work of the meeting participants:

> (Self-care is) a means whereby people take much greater responsibility for their own health based on an understanding, in their own language, of what health is all about, how to promote it, what damages it, how to protect it, and what to do when it does go wrong.

Part of the process of self-care is knowing its limits and when to get appropriate professional services. The parallel responsibility of health professionals is to provide an appropriate level and mix of services which enhance the competence and confidence of self-care behaviour in the population. The principles are applicable in all countries, but have widely different implications for programme development in developing countries as compared with the developed industrialized areas.

In many developing countries more services at appropriate care levels are needed to supplement effective self-care behaviour. On the other hand, in industrialized countries many people are overwhelmed by over-professionalized health care systems which fail to fully use the self-care resource. They may even reduce people's confidence and competence for self-care behaviour. It would be useful to study in developed countries the effects of health services on health care behaviour and health outcomes.

Comprehensive national health policies must be based on a notion of equity, specifying minimum basic standards of the quantity and quality of the social resources needed for health, including accessibility to personal health care services for all people. Any comprehensive health strategy must be firmly based in primary health care. In every country a vital component of primary health care, and all levels of health care, is the active involvement of people in maintaining their health and taking care of themselves when sick.

The recognition by both lay persons and health care professionals of the importance of self-care as an essential component of primary health care is necessary for the future development of health care systems in all countries.

## 3. DEFINITION OF SELF-CARE

A commonly accepted definition of self-care behaviour was basic to the discussion and recommendations of the meeting. The following definition was developed by the Consultation:

> Self-care in health refers to the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals.

## 4. STATE OF KNOWLEDGE REGARDING SELF-CARE BEHAVIOUR

Based on well-documented patterns of morbidity and behaviour in illness, it can be concluded that most health problems can be managed earlier, at least cost and better in the home. This is the case in all countries, but especially in the developed industrialized countries where chronic conditions, more amenable to the care and motivation of the sufferer than to professional care, dominate disease patterns. Given these prerequisites, the effectiveness of health maintenance components of self-care resides almost exclusively in individual self-care behaviour. What then do we know about this subject? What can be done to support and enhance effective self-care behaviour?

It must be recognized that a great many sources of information remain untapped, especially in the developing nations of the world. For example, the knowledge of community health workers and traditional healers regarding self-care behaviour in the populations in which they work generally has not been recorded. Likewise, the self care information available from such activities as UN sponsored national household surveys and in the large body of anthropological data has not been systematically extracted.

Much of the available information must be gleaned from investigations which were not designed specifically to study self-care behaviour. Thus, the knowledge we have is shaped by and limited to the subjects included in these investigations. Many important subjects have not received careful research attention. Nevertheless, it is possible to draw some conclusions from the data and from the knowledge of experienced persons working in practice and research settings concerned with self-care.

### 4.1 SELF-CARE IN HEALTH

The most solid information available on the effects of individual health behaviour arises from epidemiological studies and clinical trials of the influence of certain behavioural practices on mortality and morbidity (4, 19, 30, 31, 34). The negative health consequences of smoking have been extensively documented. Excessive use of alcohol both damages the body directly and is a major factor in the death and disability related to violent behaviour and to accidents, especially traffic accidents. On the other hand, regular physical exercise appears to promote health and to protect functional capacity.

There is a growing body of evidence that stress management, social involvement and/or social support provide protection from both mental and physical illness, and in general, promote health (6, 8, 9, 10, 29). The abilities to express needs and seek help when necessary also are health protective behaviours. Children and elderly persons are social groups for which these health protective skills may be especially important. Very little research has been conducted on this subject.

A generally unrecognized form of health protection is the use of natural health resources and technologies which are readily available and appropriate to health needs. Breastfeeding, herbal and other home remedies and self-help support groups are examples of such individual and group health protective behaviours. In some cases they may even be life saving. Situations were reported where people with very little income bought pharmaceutical products to treat illness which reduced the amount of money available to buy food and other necessities. When these people learned to make home remedies which were just as useful as but cheaper than commercial products, both infant mortality and morbidity dropped due to the greater intake of food which resulted.

Another form of health maintenance is the early detection of disease in order to facilitate cure when possible, and to prevent negative sequellae from occuring. This involves personal monitoring based on an understanding of major health risks and the appropriate use of preventive health services.

These various forms of health protective lifestyle behaviours depend on the availablity of correct health information to people as well as social and psychological aspects of the person's life situation. Behavioural patterns, once established, are often hard to change. There is evidence that self-help groups can be an effective form of self-care which facilitates behavioural change (17, 20, 26).

## 4.2 SELF- CARE IN ILLNESS

The controversy which may surround discussions of self-care is predominantly related to its illness behaviour component. A tendency to view self-care as behaviour opposite to and separate from professional care has contributed to the resistance to the concept by both professionals and some lay persons. This view of self-care hides the fact that while self-care during illness may be a new and challenging idea to health professionals, it is and always has been the dominant form of care in illness (12, 22, 23, 32). This view also fails to recognize that evaluation of symptoms and decisions regarding responses to symptoms are the basis of all consultation behaviour.

### 4.2.1 Decisions to do nothing about symptoms

Decisions to do nothing about symptoms have rarely been considered in investigations of behavioural responses to illness. Even though having symptoms rather than not having them is the norm and is regarded as quite compatible with good health (18), most investigations of behaviour in illness are designed with an implicit assumption that symptoms should be treated. This bias in orientation persists in spite of the self-limiting nature of most illness episodes. It affects both the design of studies as well as the interpretation of results.

When this variable was included in an investigation of behavioural responses to illness in a national population, it was found that a large proportion (37%) of the symptom episodes reported by respondents were not treated in any way. While these conditions were more often minor, it was not only trivial and rapidly passing symptoms that were not treated. (13) A similar finding has been reported from the results of at least two other studies of reactions to illness in general population groups (1, 14).

When data regarding untreated symptoms are collected and analyzed, the conclusions generally exclude the possibility that the patient evaluates the symptoms and decides that the best response is to do nothing. Furthermore, life situations which may prevent or interfere with the patient seeking treatment are rarely explored.

Self-treatment

While self-treatment accounts for the bulk of care during illness (12, 22, 23, 24) very little reliable information is available about the range and relative proportions of behaviour undertaken specifically for the purpose of caring for illness in lay populations. The bulk of the available information is limited to self-treatment with medications.

Findings reported in the literature indicate that taking medicines is the most frequent response to symptoms. The use of non-prescription drugs exceeds the use of prescription medicines by a ratio of 2:1 or greater (1, 12, 15). Traditional remedies and herbal medicines, as well as products produced by the pharmacological industry, are used widely.

It is doubtful that self-medication, although extensive, is the dominant method of self-treatment. This impression probably prevails because of a very narrow definition of self-treatment. One or more non-medication care responses were reported for 76 per cent of 3,100 common illness episodes in one investigation (14). Some of the treatment responses were directed more toward possible causes of the symptoms than purely for symptom relief.

In investigations of the use of professional services, days at home or days of bedrest have often been treated as indicators of "need" for medical care, rather than as self-care behaviour comparable to other forms of behavioural response to illness. The point should be made that remaining at home or in bed when ill may be a beneficial form of care and self-treatment rather than an indicator of "poor health" (5).

The full range of self-initiated responses to illness conditions may also be understood through a consideration of human patterns of social behaviour associated with particular problems as found in various cultural groups.

There is evidence that social support for individuals mediates between stress and illness. Social behaviours also may be a beneficial type of self-treatment for illness and a method of secondary prevention. Fifty-three percent of non-medical responses to illness recorded in a diary study of self-care involved social interactions (16). In another study, persons who reported that they usually discuss their problems with others, and those who said they find ways to rest and relax when feeling stressed, reported serious symptom episodes considerably less often than persons who said they try to reduce stress by taking medications or trying to forget their problems (13).

In developing countries, effective and satisfying methods of family care during serious or terminal illness have been documented. Social group methods of responding to stressful situations have also been described (27). In the more developed industrialized countries, the self-help or mutual aid group approach to coping with a particular health problem is increasing rapidly. This form of self-initiated care involves the giving and receiving of care in social groups organized and operated by persons with a common health problem (7, 17, 20, 26, 33).

4.2.3 Care seeking as self-treatment

The range of self-care practice must include the process of looking for and evaluating information (24). Understanding this process cannot omit decisions to contact professional providers (12, 14, 17). Lay consultation in illness is extensive, and there is evidence that lay advice influences readiness for and timing of consultations with professionals.

Social network and support influences on self-care responses to illness are apparent in data regarding decisions to contact professionals. The tendency to rely on physicians for counsel of non-medical life problems was an important factor influencing professional contacts in three population studies of self-care (13, 14, 15). The distance of the nearest residing members of the extended family also affected consultation behaviour.

The impact of the social environment on the experience of illness and self-care behaviour is an important area for exploration. The ways in which social interaction are used in active self-care should also be identified and incorporated into the operationalization and measurement of self-care behaviour.

The conceptions of lay people about health, disease and care and the variables which shape their life situation appear to be the major determinants of self-care behaviour. Yet these factors are generally ignored in health policies and programmes. During the Consultation's working sessions, repeated examples of self-care practices which grow out of the sick person's understanding of disease, or that are prevalent in the social environment, were presented. Self-care practices also depend on the resources available for developing treatment procedures. One report from a developing country reminded us that only the individual knows exactly how he/she feels when in good health or after the onset of illness. When there is ill-health, it is the individual who takes the first responsibility for decisions regarding care and determines the kind of care. It was noted that people have always held holistic views about the human being. They therefore get upset by the tendency of most professionals to regard the disease as the object of intervention (care and/or cure) and not the person who has the disease. It is important to listen to the people about their concepts of health, disease and health care.

### 4.3 THE FAMILY AND SELF-CARE BEHAVIOUR

Most self-care behaviour takes place in a family environment. It is in the family that health attitudes are first socialized, health practices are learned and most health care is provided. (23) The family is the basic source of social support and contact, both of which influence health status and health behaviour. Because self-care takes place in families, health policies and programmes to enhance self-care behaviour must be directed toward supporting family units. The type and amount of care provided in a given family will be a function of the acute and/or chronic morbidity experience of its members, their lifestyles, value system, feelings of responsibility, financial situation and the community support services available.

The quality of the family environment will either support or reduce the likelihood that self-care can be practiced safely and effectively. For example, the home, the physical space in which self-care is practiced, is an important component of the environment. Another important influence is the family's educational environment, the access to information of family members. A third important factor affecting family self-care is the time available to its members. The question of who functions on whose behalf in the family may influence both the quality of the family care provided and equity of opportunity among family members. The type and amount of family support services available in the community will affect this situation.

Some families can be quite flexible. With the help of friends and other non-professionals in their social network, they manage extremely well. Many other families with a fragile member become socially fragile families whose cohesion and efficiency break down, further limiting their possibilities. Whether the onset of illness or injury is sudden or gradual may affect the family's capacity to adapt and mobilize resources and methods to cope with the situation.

Since the main caring role in families continues to be fulfilled by the wife/mother, women must be involved in the development of primary health care systems. As providers and users, they can insure that new approaches address important concerns in a way that assures acceptance and participation. Another important reason for assuring the involvement of women in programme development is that they are not only key providers of health care in families, but also in community health care facilities. Another reason is related to the problem mentioned above of equity of responsibilities within families.

When women combine the caring role of the wife/mother with employment, they are often subjected to burdensome routines. Studies in one country revealed that employed women have on the average only two hours and fifty minutes of free time a day. Three times more women than men reported having almost no free time. Similar findings regarding the burdens of double work have been reported from investigations in other countries.

Generally, it may be concluded that families faced with taking care of a dependent or disabled member, or depending on a medical or social institution because it is easier, must enter a process of negotiation regarding the responsibilities to be shared by the dependent member, other family members and other groups or institutions. When the distribution of caring functions is uneven and burdensome, the self-care of both the care giver and the recipient of care will be negatively affected.

## 5. ISSUES

There are many issues to consider related to policies and methods designed to enhance self-care behaviour in various population groups.

### 5.1 CONCEPTUAL ISSUES

It is somewhat artificial to consider conceptual issues separately from policy and practice issues. However, since the former define and shape the latter, the concepts and principles accepted by policy makers will determine the nature and functioning of programmes developed in a particular subject area. The following are major conceptual issues which the participants considered most important.

Perhaps the basic self-care issue to consider relates to the factors which determine health status. The participants of this meeting emphasized that the barriers to health are social, economic and political. This means that many forms of non-professional care and action contribute more to the health of populations than does professional treatment. The recognition of this fact is essential to the development of policies which support health enhancing behaviour.

The definitional issue arising from this fact centres on the content of self-care. Much of lay health care is the material of everyday life. At the personal level, the individual alone determines the balance of behavioural patterns most health enhancing in the context of available resources, personal values and preferences. At the group level, effective self-care behaviour is active endeavour to achieve the perceived health needs of the community. At the core of this issue lies the right of definition, who defines the problem and who identifies the solution. Health care policies and services must arise from the felt needs and goals of the people in order to assure an appropriate priority assessment free of vested interests and to attain acceptance in the community. If insufficient or polluted food supplies endanger the health of the population, increasing the supply or level of professional services is not a socially relevant health enhancing response.

Many self-care practices are not considered by professionals as health practices. In some instances there will be proof that the practices do not promote health and may be damaging. In other instances, however, the value of lay practices is ignored or denied because of medical or technological bias which has not allowed for a balanced consideration of alternative approaches to problems. Recognition of the validity and contribution of lay health experience and practices among professional health workers is an important issue. Self-care competence may be undermined by professional bias and control.

An era has now been entered when many procedures and techniques formerly performed by professionals are now performed by individuals for themselves or by family members caring for individuals. Many people see complicated legal and administrative issues in this development. Attempts to achieve clarity by definition and/or rules which limit self-care practices are not successful because of the wide and constantly changing range of self-care. A physician participant in the meeting pointed out that it is more appropriate and relevant to define the nature of a medical act and identify the appropriate role and responsibilities of professionals than to attempt to develop rules and limitations for the countless variety of lay care situations.

All of the above issues relate to a concept of self-care as an appropriate technology for health. The principle involved in this concept is that people caring for their health should have access to the level of care and technology most useful to their needs as they vary by family situation. That is, the care process for any given problem would involve the least amount of intervention possible to achieve the desired outcome. The knowledge necessary for the care response would be easily communicated with appropriate support services provided to the family unit. Technological inputs would not be limited to one group or another, but determined solely on the basis of the relevant level of care for a given situation. This would minimize interventions using complex technology and reduce the drain on financial and logistic resources of health care systems.

Since the conceptualization of self-care as appropriate technology contains the implicit assumption of relevant inputs of treatment and support services and protection from irrelevant or unnecessary inputs, it addresses the issue of equitable access to professional

services. The issue of equitable access has been raised by persons concerned that the concept of self-care will be used as an excuse for denying or reducing health and social services to certain groups of people in need. The concern is that self-care would become part of a process of "blaming the victim" in order for governments to avoid public responsibility.

The particular concern is that poor health would be ascribed to people's ignorance, poor motivation, and unhealthy lifestyles so that they, especially the poor, would be blamed for their own poor health and held responsible for its improvement. Any such use of the concept of self-care is a misuse and abuse of the concept, and is alien to the perspectives on self-care discussed in this report.

### 5.2 POLICY AND PRACTICE ISSUES

The policy issue which is most relevant to consider at this time is the subject of barriers which inhibit effective self-care. These barriers may be: 1) legal; 2) de facto administrative or professional practices; or 3) unintended effects of professional treatments. Examples of legal barriers which prohibit persons from practicing or obtaining the type of care they wish have been documented in relation to childbirth, terminal illness, the right to die, and equitable access to alternative treatment or practitioners' services.

In many instances where there are no actual legal barriers, de facto practices either directly inhibit or seriously interfere with effective self-care behaviour. One example is professional attitudes that inhibit disclosure of health care information to lay people or limit health care skills in order to maintain professional control and lay dependency.

A third type of barrier occurs from unintended effects of professional treatment. For example, unnecessary treatments and medicines often are prescribed when advice, comfort and sensible home remedies might be equally or more effective. Health professionals need to realize that the amount families spend on vitamin tonics, cough medicines, cold formulas, diarrhoeal drugs, needless injections and frequent trips to health centres for problems they could manage themselves actually may weaken the health of family members by leaving less money to spend on food, social support and relaxation.

A related issue concerns the rights of individuals to practice effective self-care irrespective of the economic interests of others or the interests of particular social groups. Thus, concerns regarding productivity or public spending should not prevent people from the right and economic security to remain at home and care for themselves during illness. Neither should the interest of various professional groups or organized religious bodies inhibit access to the means necessary for effective self-care. The latter point includes the right of access to appropriate technologies in the home for self and family care, including childbirth.

## 6. ENHANCING EFFECTIVE SELF-CARE BEHAVIOUR

The discussion and recommendations were organized around four subject areas: 1) policy in support of self-care; 2) the role of education; 3) the impact of professional care; and 4) a research base for informed policy and programme development.

### 6.1 POLICY IN SUPPORT OF SELF-CARE

Public policies in support of self-care must function to demystify health care, creating enabling environments in which people can more readily promote their health and care for themselves during illness (28). This means first and foremost, that the distribution of resources to health care systems must be altered from excessive concentration on disease-oriented professional approaches to health care, to systems which provide more information and transfer of technical skills to the lay population, provide relevant support services for family care and viably integrate lay and professional care.

Health enhancing policy, policy which enables people to take greater responsibility for their own health, first recognizes the contribution and potential of self-care. The policy must be rooted in the lay population, which means that the people's preferences, priorities and solution strategies must be integrated into the decision-making process forming a basis

for the type, mix and implementation of public health programmes. A participatory and rooted policy requires that ordinary people, heretofore excluded from the development of public policy, be meaningfully integrated into the process.

6.1.1 Legislative policy

Meaningful endeavours to enhance health-related decision-making and care skills in lay populations cannot occur without adequate funds and personnel. The starting point for all of the ideas and recommendations arising from the work of this Consultation is the process of adopting national public policies supportive of self-care.

The participants emphasized that it is not only relevant to consider allocation of resources to health service systems, but also the important role which departments of education, social services, housing and income maintenance all have to play in policies to support and strengthen self-care skills.

Perhaps the second priority is to examine existing laws to determine if they explicitly or implicitly create and/or maintain barriers to effective self-care in the population. Many health laws were designed in another era for reasons no longer relevant. Some laws created to protect the public from certain dangerous practices now function to retard innovation by excluding or limiting levels or types of care better suited to achieving healthier populations. Health agencies, often imbalanced in the range of health professionals who operate them, have been reluctant to loosen the professional grip on medical knowledge. Other departments, such as education or agriculture have sometimes been more conscientious in providing useful and useable health information to the public.

Lay people often must consult professionals to obtain certificates or statements to legitimate their disease or allow access to particular caring facilities, services or medications. The whole question of legitimation should be examined to determine the extent to which it functions as a barrier to effective self-care and causes costly unnecessary use of expensive and sometimes scarce professional services. In some respects, what is called for is an enlargement of the concept of technology assessment to include the principle that a given service should be available at the lowest possible level of care where the safety of the person exposed to the treatment or care service will be assured.

Examples of other areas where legal barriers might interfere with self-care are in cases of illiteracy and in situations where lay people cannot gain access to their health records. While literacy is an important life skill and should be a right of all people, it is not essential to the practice of effective self-care in most situations and should not serve as a barrier to self-care resources.

Lay persons cannot be expected to practice optimum self-care and function effectively on their own behalf when information about the condition of their health and decisions regarding treatment are kept secret. Denying patients access to full information about health conditions and treatment options cause them to miss opportunities for learning, and mystifies disease, It may also reduce lay people's confidence in professional judgement. Health professionals should be encouraged to teach their patients and clients to become experts on their own disease states, risk factors and health status.

The participants concluded that the important subject of appropriate technology must now be addressed both by removing any legal barriers to appropriate transfer of technology, and by establishing the legal foundation and relevant budgetary allocations for access to the technology best suited to every level of care, while limiting excessive use of technology at any level of care. The transfer of appropriate technology for self-care coupled with avoidance of over-development and overuse of technologically intensive professional services is crucial for both developing and industrial countries.

6.1.2 Administrative policy

If the goal of health systems is both to support and complement lay care, then health services must be planned to be supportive rather than leaving the people behind or dragging them along.

Encouragement of self-care and self-health requires new styles of government bureaucratic practice. A keen sense of organizational and professional power and a disposition to restrain its use is crucial. Willingness to participate in prolonged advisory-consultative processes that lead to articulation of mutual interests is essential. The capacity to play the dual and sometimes conflicting roles of advocate and accountability source is the most difficult test.

Removal of direct legal barriers and the passage of enabling legislation accounts for only one level of the health policy changes to be accomplished in support of self-care. It is often the manner in which law is interpreted in the form of rules and regulations governing institutions, professional practice and public services that creates barriers to self-care. Sometimes, there is not even a legislative background, but rather de facto practices assume the force of law through customary approaches or usefulness. It is therefore important that governments: 1) assure accessible avenues for lay people to acquire the knowledge and skills to support and improve self-care; and 2) remove disincentives to self-care that may be embodied in health insurance plans, professional practice acts, administrative guidelines and the structure of health services.

At least one Member State has established a comprehensive policy on the health promotion component of self-care which may provide a transferable model for other Member States.

Four strategies were identified for this national programme. The first strategy is to inform and equip lay people so that they can deal with lifestyle issues. This represents the traditional health education approach. Another strategy is to promote a social climate that supports healthy lifestyles. This is susceptible to broad interpretation to include positive lifestyle advertising as well as influencing the conditions under which food, alcohol, tobacco and other consumer products are marketed.

A third strategy is to support self-help and citizen participation in health promotion. The fourth strategy is to promote the adoption of health education practices within health care, social welfare and other established service programmes.

The programme operates in two ways. The Government carries out a variety of operational activities that include advertising, information delivery and development of special programme materials. Alternatively, it provides financial grants to citizen groups to enable them to engage in health promotion activities through their own membership and contacts. Within this general frame of reference the Minister of Health has broad discretion to determine how the health promotion programme will operate.

During the time that these policies have guided developments some initial experience has been gained in using public policy to encourage self-care and self-help. This experience arises from interaction with citizen groups which have received financial grants as well as groups with which there are cooperative or shared projects. This programme thus has built in mechanisms for participatory public policy development.

Practical ways in which sensitive public policy can encourage self-care and self-help through organized groups are:

1) official recognition which gives self-help groups the strength that comes from legitimacy;

2) consultation on goals, activities, organization and sources of information which opens to such groups the information base and communication networks accessible to large bureaucracies;

3) financial grants for organization, training and production of materials which help to adjust the power balance between informal networks and organized institutions;

4) well-conceived programme materials for use in advocacy, awareness building and training which provide working tools to harness the energy of such groups; and

5) joint or cooperative projects under which planning, financing and work are shared, and thus linking citizen flexibility and creativity with the information and funding capacity of government.

It is useful in working with citizen groups to recognize the significant differences between them and to adjust the approach accordingly. There are differences in their specific interests in health, the extent to which they are organized or bureaucratized, and the degree to which interests are focussed on the immediate concerns of members or on those of the wider community.

Effective policy to encourage the growth of self-help requires from health authorities the capacity both to lead and to follow. The knowledge base and communications networks of large institutions may lead them to recognize a health issue before it finds grassroots expression. Then the government has an obligation to lead. In other cases, citizen groups are able to define issues that are more creative and sensitive to reality than governments can. In this event, extensive consultation should precede programme formulation.

## 9.2 ROLE OF EDUCATION

The importance of Member States accepting health as a fundamental goal of public education was a priority emphasized repeatedly during the course of Consultation. The concept of health literacy was introduced. This concept, defined as a basic knowledge of and control over one's personal health situation, is useful for programme planning and evaluation. The definition of the term health literacy contains three elements which are essential to successful endeavours to improve self-care behaviour in populations. These elements are: 1) basic knowledge, which implies a certain level of assimilated health information and understanding; 2) control, which suggests enablement or empowerment, so that people have the opportunity to practice responsible and effective self-care behaviour; and, 3) situation relevance, which recognizes the wide range of health needs and available health resources in different population groups.

What is being referred to here is education for health; education which is dynamic, relevant to the situation and adapted to changes in the situation. Education for health prepares people to recognize what they must do to maintain their health and care for themselves when ill, and enables them to act on that recognition. This education most often should be integrated into formal education systems, but this is not always possible. The ability to read is an important life skill which increases the opportunities to practice more effective self-care both because it increases the ability of individuals to obtain health sustaining resources and because it increases access to information.

However, the ability to read is not essential to education for health and should never be a barrier to providing people with health enhancing information and skills. Professional persons of all types sometimes fail to recognize that uninformed people and people facing serious obstacles in their life situations are not unintelligent and unmotivated. Effective health promotion must be based on the beliefs, experience and resources of specific population groups. People cannot be expected to change behaviour or adopt new behaviours if they do not perceive a logical basis for the changes, or if the changes are inconsistent with their priorities. Self-care education might, therefore, be defined as a social process which enables people to define their health situation, identify problems as they arise and find solutions either by caring for themselves, obtaining appropriate health services or in social action directed toward the specific problem.

### 9.2.1 Utilization of natural environments for education regarding self-care

Education for health must, as suggested above, start where the people are. This means knowing and building on the self-care behaviour which already exists in the community. It means using available resources and communicating with people in their natural environments to learn the community's health problems and priorities. Education which empowers people to act on behalf of their health must use the settings where people learn most easily and naturally. Thus three particularly important learning environments are the home, schools and the workplace. There are many more. Opportunities to utilize the arts, the media, community centres, health service and other settings should not be overlooked.

The type of self-care education proposed by the participants is not limited to dissemination of health information. Of course, information on health and disease will be transferred, but the factual content is less important than the skills which are learned, skills of problem solving and, even more important, problem posing. Effective self-care education helps people learn to analyze the factors which affect their health and well-being,

and to take action to change these factors. A self-care education programme thus might contain content to help people:

1) Regain appreciation for those home remedies and preventive traditions that are effective and inexpensive. For example:

- breastfeeding
- herbal and other traditional remedies
- homemade crutches and artifical limbs.

2) Find ways to improve and build upon effective traditional forms of healing and prevention, especially where resources and health services are severely limited.

3) Help people learn to weigh risks and costs against benefits and understand the range of options available to them.

4) Recognize their own capacities, and limitations, knowing where and how to seek assistance effectively.

5) Gain the confidence, understanding, and collective strength to seek from institutions, doctors, health workers, and traditional healers the referral services they need; and to obtain the information, supplies and support they need for more effective self-care.

6) Obtain and make good use of available resources and information from verbal and non-verbal teaching materials or from community health workers skilled in informal education methods. Information should be made available on:

- techniques for analysing situations and solving problems.
- nutrition, hygiene, sanitation, and care during pregnancy, birth and early childhood.
- diagnosis, treatment, and prevention of common health problems.
- using readily available local materials, technologies and practices to enhance and protect health.
- what constitutes correct use, misuse, and overuse of medicines, both traditional and modern.
- prevention and rehabilitation of common disabilities.
- how to avoid being uninformed, misled, overcharged or over-treated by health professionals, or lay healers.
- the processes of sickness and health, the body and how it works, and the limitations of cure in contrast to prevention.

In order to facilitate early socialization in these important self-care skills and practices, parents and prospective parents must be given the chance to learn how to help their children learn self-reliance, group participation, and self-care skills.

Health education often has referred to courses or classes with specific health content. Education for health must extend beyond the limited time and content that can be presented in specific health classes. Most of the subjects taught in schools affect health or have health-relevant aspects. Health should not be presented as only a special subject, but also integrated into the entire school curriculum.

Health-relevant problem identification and problem solving skills apply in many subject areas. Examples related to health can be used in training in arithmetic skills and logical thinking. Safety and the importance of social interaction/support are subjects which can be emphasized in social studies, crafts, sports, speech and other courses.

The school health education programme includes not only health instruction but also the school health services and cooperative activites with homes and communities. The content of general education at all levels, especially at primary and secondary schools and teacher training colleges should include suitable basic health information on the normal functions of the human body, disease causation, disease prevention, health promotion, environmental sanitation, social relations, and basic procedures to recognize and contain disease and appropriately use professional health resources.

### 6.2.2 Health education directed toward special populations or specific problems

Even when health care is integrated in general school curricula, there will be situations which require specific health education programmes. The curriculum approach best suited to self-care education contains both integrated and separate health content. Many people face specific health problems or practice health damaging behaviours which they want to change. These are instances where specific health education or behavioural change programmes are appropriate. This does not mean that these specialized programmes should be exclusively didactic. Mutual aid or peer learning may be more effective health promotion approaches for many problems.

Not only specific health problems, but also certain target groups may benefit from special self-care education. Children and adolescents may benefit from self care education using peer learning techniques to discourage smoking or to encourage use of seat belts. The elderly, a specially vulnerable group in illness, may benefit from learning more about judging symptoms, caution in the use of medicines, appropriate consultation and assertiveness in obtaining information and maintaining their integrity in professional encounters. Finally, support groups are a form of self-care education when they help people coping with crises to maintain better health behaviour.

### 6.2.3 Information systems (media)

Education for health, in order to achieve wide penetration in the community, must reach the people through a variety of communication techniques. The methods used should take into account cultural ways people learn, for example, story-telling, plays and music.

The mass media have become major sources of information and should form a part of the strategy to expand self-care education. The impact of the media, however, can have the opposite effect if potentially health damaging practices are commonly presented. A part of the strategy to use the media should be to analyze the content and remove harmful aspects of advertising or the use of popular figures to promote practices injurious to health.

The indigenous media is an important resource. Local talent should be used. Developing countries, should avoid sophisticated media equipment which may become obsolete, difficult to service or expensive to maintain. The concept of self-care as appropriate technology applies to information transfer as well as to treatment procedures.

## 6.3 SELF-CARE IN THE CONTEXT OF PROFESSIONAL TREATMENT

Contrary to the concept of self-care as behaviour which only preceeds or substitutes for professional care, self-care, as suggested above is a vital component of all levels of care. This is not to say that self-care is not affected by professional care. It may be inhibited or enhanced both in quality and in quantity by the attitudes and performance of professional health care providers.

### 6.3.1 Impact of professional attitudes and behaviour

Self-care behaviour arises from the knowledge and the experience of individuals functioning in social groups. It forms the bulk of all health care. Yet professionals generally do not take it seriously. They tend to ignore its existence, downgrade its importance or even actively denigrade it. Many professionals, reject outright any practice or discipline of knowledge that falls outside of their view of what is scientific. This situation prevails even though professional health care is not always scientific. Unproved, even untested medical treatments are sometimes standard practice for years before being determined ineffective and even harmful.

These contradictions in the attitudes and judgements of professionals regarding lay and medical care may both undermine people's confidence in their own self-care competence and also create doubts and suspicions regarding professional care. Thus, one of the bigger tasks in the process of establishing integrated and effective lay and professional health care systems is the nurturing of attitudes which are receptive toward lay care and more balanced and consistent regarding professional care.

6.3.2 Professional education

Professional attitudes toward health, disease and care are developed and nurtured during the training period. Therefore, a key strategy for the enhancement of lay health care behaviour is an altered approach to the concept of self-care in the educational programmes of health professionals. Professional education programmes are focussed on the scientific and technical information relevant to the treatment approaches and practices of the respective disciplines. This has resulted in a medical and professional orientation to concepts of health care. Providers of health care thus have the perception that health care is centered in the services they provide, rather than in the self-care behaviour of lay persons.

One way to address this problem is to define medical care, nursing care and other types of professional care, specifically in the context of self-care, as services which supplement individuals' health promotion and health care behaviour in illness. Furthermore, professional training programmes must incorporate teaching strategies which reorient professional roles toward teaching functions rather than the dominant emphasis on providing services to people. Training programmes designed to help professionals who provide services which facilitate effective self-care behaviour must consider:

1) the social and psychological aspects of healing and effective self-care;

2) the unique knowledge and perception that individuals have regarding the state of their health;

3) the right of individuals to full information regarding the state of their health, treatment options, and outcomes in relation to specific diseases;

4) the inhibiting effects which professional behaviour can have on lay people's knowledge of health and illness and confidence to act on their own behalf in health maintenance and treatment of illness; and,

5) the importance of appropriate technology to effective care in illness.

Students should leave professional training programmes with an awareness that most patients (at least in primary care practice situations) already will have responded to their illness/health conditions with one or more self-care strategies. Students in the health professions should acquire a deep sense of the self-limiting character of most illnesses and the appropriateness of exclusively self-care interventions for most illness episodes.

Technologically oriented medical practice is a problem of a different magnitude in developing countries which try to replicate the medical services of the developed world. It is important to alter the medical school curricula of these countries to reflect the countries' primary care needs.

In addition to orthodox scientific medical practices, students of professional training programmes should be exposed to traditional and "alternative" health practices. The introduction of the concept of unified and integrated health care in training institutions will create awareness of and more positive attitudes among professionals towards self-care.

6.4 A RESEARCH BASE FOR INFORMED POLICY AND PROGRAMME DEVELOPMENT

While a great deal is known about the volume of self-care practices in various national settings, very little is known about the content and effectiveness of self-care. Similarly, knowledge about the factors which determine the type and extent of self-care is limited. The collection of valid and reliable self-care data thus should be a priority at this stage of the development of health service systems.

Baseline data

Any attempt to support self-care behaviour and to implement integrated lay and professional health care systems must take into account concepts in the lay population regarding health and the causes of disease. The type and amount of self-care practices must be charted in different population groups. These studies should examine alternative forms of self-care within nations and between areas of the world, recognizing that there are no country-specific patterns of self-care but that the within-country differences will often be as great as those between countries.

These baseline studies must recognize that self-care involves not only treatment of minor conditions, (primary care), but operates at every level of care. Decisions regarding whether or not to obtain services, the type of provider contacted and adherence to professional advice are self-judgements. Lay peoples' expectations of and confidence in themselves and in professionals often determine health care outcomes.

Self-care behaviour during periods of crisis and rehabilitation behaviour following disease or injury are special areas to study. Research related to chronic or serious illness should focus specifically on the interaction between self-care and professional care. Since self-care is a crucial variable in chronic disease and long-term care, its content must be understood. For example, more knowledge is needed about the specific clinical situations under which self-care would represent an equally efficacious mode of response. Likewise, the clinically focussed model of care should be examined in relation to an intersectoral approach which integrates medical and social forms of care.

6.4.2 Analytical studies

As explained earlier a great deal more needs to be known about the forces which shape self-care behavioural practices. Self-care has been narrowly defined in an approximation of the medical model, as the use of dietary or chemical substances, or of mechanical appliances to treat or respond to illness. When components of the broader range of care and health enhancement are omitted from investigations, it makes it more difficult to identify factors which shape behaviour. Also, the limited number and type of "independent" variables included in investigations have not added much depth to available information on self-care.

To identify the factors which shape self-care behaviour and their relative contribution to alternative patterns of care, investigations must be designed to:

1) examine the extent to which existing social policies, the organization of health services and community decision-making procedures either enhance or impede personal and family self-care;

2) identify the psychological, social network and cultural factors that determine lay attitudes and self-care behaviour in various populations,

3) identify the factors that influence the adoption of new health practices within communities,

4) examine the influence on self-care of the types, scope and availability of health care systems in the communities,

5) examine the levels of contact and modes of interaction best suited to sharing information and skills with the lay public.

The content of training programmes for professional health workers and professional behaviour in treatment settings must be included in investigations of factors that shape behavioural responses to illness. The content of professional curricula as well as the attitudes and frame of mind acquired in the course of training programmes may influence self-care behaviour, the tendency to use professional services and lay behaviour in professional treatment. Professional fears about more active lay involvement in health care and the influence it may have on the organization of health care systems may limit the transfer of information and skills which lay people need to practice effective self-care behaviour.

A body of valid and reliable self-care data can emerge only from investigations in which valid and reliable operational measures of self-care are used to collect data from probability samples of general populations. Since little is know about the content of self-care, qualitative studies are needed to define the range of behaviour in illness. Uniform definitions of self-care variables must emerge before factors that determine alternative forms of care can be effectively analyzed.

### 6.4.3 Evaluation studies

Evaluation research on the subject of self-care must be concerned with both the content of the care and with the effects on self-care of professional care and public policies. Safety is an issue frequently raised regarding self-care. While we know little about the safety of self treatments, the limited available information suggests that self-care practices are generally safe and appropriate. The relevant point is that all health care treatments should be evaluated, whether practiced by lay or professional persons. Evaluation has rarely occurred in either case, even though questions of safety, efficacy and cost effectiveness cannot be answered without it.

When self-care is considered as appropriate technology, the importance of evaluation to safety, efficacy and cost effectiveness is immediately clear. There is, for example, a substantial interest in moving some technology from the professional sector to the lay sector. A growing industry is converting professional technology for lay access, a positive development as long as careful work is done to ensure that the products and procedures which are being produced are safe and effective. Since these developments will be accompanied by a complicated array of competing interests, some of them commercial, the establishment of a gatekeeping process in relation to health care technology is necessary to protect the public interest.

Identification of appropriate criteria for evaluating different health activities, self care practices and health care systems must precede the design of evaluation studies. Evaluation should be a continuous process taking into account both lay and professional expectations and performance.

### 6.4.4 Policy studies

Most of the discussion has centred on evaluation of specific practices, procedures or programmes. It is equally essential to maintain a societal perspective in the process of evaluation. Thus, Member States should monitor their laws, administrative procedures, professional practices and mix of professional services to assess their impact on self-care patterns in various groups. Periodic reviews to assess progress in terms of self-care enhancing policy, education and professional practice will be needed. Studies of the impact of self-care programmes on sub-groups of the population such as disabled persons should be incorporated into the evaluation process to assure that needs of particular groups are integrated into programme implementation.

## 7. RECOMMENDATIONS

Based on the presentations and deliberations of this Consultation, the participants developed recommendations for each of the four major subject areas concerned with enhancing effective self-care behaviour.

Achieving effective and ethical public policies in health development that take into account the lay contributions to health care

1) Member States should be encouraged to recognize the role and importance of self-care as an essential part of a strategy for reaching health for all.

2) Member States should be encouraged to review their existing laws and take active steps to eliminate the barriers to and encourage the acquisition of self-care knowledge and skills among their citizens. WHO should assemble representatives of member states to discuss these issues.

3) Member States should be encouraged to facilitate effective self-care in their populations by:

- elimination of financial disincentives to self-care;
- elimination of illiteracy;
- providing access to appropriate technology for safe self-care;
- providing support services to enhance self care and the ability of families to participate appropriately and effectively in care-giving.

4) Governments should centre their health policies and allocation of resources in systems that give highest priority to primary health care programmes that effectively build upon the lay health resource.

5) Each nation, state and local government should identify local health resources and technologies appropriate for effective health care based on the principle of the least amount of intervention (technological procedures, drugs, costs) needed to achieve a particular health outcome.

6) WHO should work with other international agencies, such as ILO, FAO, UNESCO, UNFPA, and UNICEF, to encourage member states to develop programmes which assist families with the enhancement of their health care functions.

Effective strategies for raising public competence in self-care through formal education

1) Member States should be encouraged to accept "health literacy" as a fundamental goal of public education. To achieve this, pre-school and school-based education should offer opportunities to learn about self-care both directly as a discrete component of the curriculum and indirectly drawing on relevant aspects of other subjects.

2) WHO should advise Member States to recognize the role of self-care in the achievement of HFA/2000 goals by integrating health education and self-care into all categorical health programme objectives, activities and targets.

3) Effective self-care education must be rooted in local culture, priorities and values. It must start with the people, recognizing and building on their concepts of health, disease and effective care.

4) Teacher training programmes should include education for the teaching of self-reliance and self-care skills at all levels of formal education systems.

5) Opportunities should be developed both within and outside the formal educational system to help parents and prospective parents learn how to educate their children for self-reliance and self-care.

6) Carefully planned mass media programmes using TV, radio, press etc. should increase awareness of self care and reinforce positive self-care practices in the population. The effectiveness of these programmes should be monitored continuously.

7) Government-funded health education should be expanded to include self-care education directed when necessary at particular target groups, using educational methods best suited to learning in the group and using local media resources wherever possible.

8) Worksites, medical facilities, religious centres and other community settings provide opportunities which should be used for education in health promotion and illness related components of self-care.

Adapting the functions of health care professionals in ways which maintain or enhance self-care competence

1) Institutions concerned with training health workers should seek to integrate self-care concepts into their curricula. Ways in which this might be accomplished could include:

a. The incorporation of self-care material and techniques in medical and other health professional textbooks.

b. Education in communication skills.

c. Institutes/courses for the teaching of skills for integrating self-care in clinical practice.

d. Using well-documented case studies of application in clinical practice (e.g. Williamson, Tudor-Hart, J. Fry, etc.).

2) Undergraduate and post-graduate curricula for health providers should include field studies and practical experience related to self-care behaviour and appropriate educational techniques for enhancing self-care practices and lay participation in health care.

3) WHO should request member countries to initiate a process of dialogue with professional organizations, public health agencies, health service agencies, health insurance systems, professional and paraprofessional training programmes, school authorities and relevant volunteer agencies and consumer groups regarding the development of strategies for advancing concepts of self-care. In particular it would be valuable for WHO and member countries to initiate survey and research activities concerned with self-care resources in the health continuum. WHO should request member countries to report annually on the implementation of self-care within their health, education and social service systems. WHO should report annually to the World Health Assembly on progress in implementing the self-care concept.

Research and evaluation priorities and methodological considerations

1) Governments should commission studies on self-care behaviour in various communities, target groups, and groups of people with specific risk status or diseases so that the potential for self-care can be better understood. These studies should investigate:

a. the influence of social, cultural and psychological factors on patterns of health behaviour and symptom-response.

b. variations in symptom-response patterns between cultures.

c. individual vs. family roles in self-care practice.

d. personal motivations associated with self-care skill and practices.

e. the impact of health programmes on lay care in communities.

f. the effectiveness of specific educational technologies in different cultural situations.

g. cost-effectiveness of self-care intervention in comparison with other interventions for particular health problems, with careful attention to avoiding any approaches to self-care which "blame the victim".

2) Research is needed to clarify the continuum of "primary care" and to identify potential differences in the dimensions of primary care in the developed countries in relation to the developing countries.

3) WHO should encourage Member States to evaluate self-care as well as professional care techniques.

4) WHO should encourage Member States to stimulate the comparison of conventional medical treatment and alternative medical techniques to identify options that are cost effective, safe and acceptable to communities.

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