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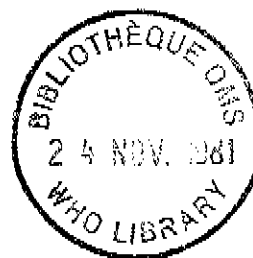
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APPROPRIATE LEVELS FOR CONTINUING CARE OF THE ELDERLY

Report on a WHO Working Group

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1. Introduction

This Working Group was the first WHO meeting convened to discuss technical aspects of the care of the elderly since the adoption of the Declaration of Alma-Ata, which called for a reorientation of WHO programmes and for new strategies to promote primary health care in Europe. In view of the increasing number of elderly persons in the Member States of the WHO European Region, and consequently the growing demand on health resources on the part of the elderly population, new strategies are urgently needed to ensure that the health of elderly persons is promoted and maintained.

The principles embodied in the Declaration of Alma-Ata suggest that greater attention should be paid to family and community care supported by the primary health care services. Nevertheless, the need for institutional care is likely to persist and, because of the aging of the population, to increase over the next decades. It is therefore important to maintain a balance between family, community and institutional care so as to ensure that services are available at each level and that they respond flexibly to the varied demands of elderly persons in different age groups requiring forms of care appropriate to their varying needs. The Working Group was asked to examine the potential contribution of informal methods of care and to consider ways of integrating institutional and primary health care with the aim of ensuring effective community-based services for the continuing care of the elderly.

The participants were welcomed by Dr R. Mattheis on behalf of the Senate and City of Berlin (West). She emphasized the relevance of the topic to the European Region, and particularly to Berlin, which had a high proportion of elderly people among its population. Dr H. Hermanova, Consultant, Health Care of the Elderly, WHO Regional Office for Europe, on behalf of the Regional Director, Dr Leo A. Kaprio, explained the scope and purpose of the meeting. Dr R.J. van Zonneveld was elected Chairman and Dr H.A. Paul Vice-Chairman. Dr R. Illsley acted as Rapporteur (a list of participants is given in the Annex).

The Working Group discussed working papers and presentations on the following topics:

- the needs of the elderly as defined by population studies;
- the manpower and institutional resources required for continuing care;
- self-care;
- informal care;
- formal care systems;
- the integration of institutional care with primary health care services.

The participants drew upon the material contained in these presentations and upon their own experience and knowledge to elucidate general principles and to identify particular problems requiring action or further research.

2. Appropriate levels of continuing care: general principles

For reasons which are irrelevant to the needs and problems of the elderly, but which stem from administrative and professional concerns, there is a tendency to compartmentalize the provision of care. In this report, too, self-care, family care and other types of lay care and the formal service sector are dealt with separately. Elderly persons, however, like other clients of our health and social services, perceive needs which do not arise as separate problems neatly labelled "medical", "nursing" or "social" and which are not obviously the separate concern of the family, the health service or the social services. The notion of "appropriate levels of continuing care" implies that, while care should be available from a variety of sources to meet a range of needs, there should be no sharp or artificial divisions.

2.1 Fundamental principles

Care should be responsive to the needs of the individual and not to the needs of the provider of care or the administrative or professional requirements of agencies.

2.1.1 Objective measurements of needs

The objective measurement of needs and the specialized training of persons to meet those needs are clearly essential, but felt needs must be the starting-point of acceptable care. This cannot be achieved unless elderly persons are involved both in the assessment of need and in the choice between alternative modes of care.

2.1.2 Involvement of the consumer: subjective aspects

Elderly persons are rarely involved in the design and evaluation of health services, with the frequent result that services are not sensitive to their requirements and feelings. Non-involvement has a further unfortunate consequence, namely that the elderly are seen as recipients of care but rarely as care givers in their own right. Partly for biological reasons, but largely because society excludes elderly persons from making significant contributions to the social and economic life of the community, the elderly are relatively powerless in modern societies and subject to unequal relationships in their daily lives. Evidence has accumulated which demonstrates that reciprocity is highly valued by elderly persons and that care is more readily acceptable when care can also be given.

The urge to keep control over one's own life and daily activities and to retain the possibility of reciprocal relationships is partly responsible for the almost universal desire of elderly people to remain in their own homes, to care for themselves, and be cared for by family and friends, as long as possible.

2.2 Links between informal and formal care

While governments, professionals and pressure groups (for a variety of good and bad reasons) have newly discovered the concepts of self-care and family care, old people have continued doggedly to care for themselves within their familiar environments. Self-care, family care and care provided by neighbours and volunteers constitutes an overwhelming proportion of all care available to the elderly. Our over-stretched formal services would collapse if such informal care were to diminish. We should accept this reality, together with the clear desire of most old people to remain in their own homes or in familiar circumstances even to the point of death. The aim of formal services should be to support, not to replace, informal care unless there are substantial contraindications.

Ideally, self-care, family care and other informal care should be closely interwoven with each other and with the formal services. Indeed, the principle of interweaving is perhaps most necessary, because it is most lacking, within the formal services. We are very conscious of the gaps and the barriers between the health and the social services and between primary care and the various subdivisions of residential, hospital and long-stay institutions. Ease of transition within the full range of informal and formal services and between individual services should be the goal of health service organization.

The existence of services and of personnel trained to provide a specific type of care, though valuable in itself, should not obscure the overriding importance of impersonal necessities which maintain the independence and living standards basic to human social life. Money provides the essential commodities for a dignified and secure life, and appropriate housing facilities help to ensure an independent lifestyle and a continuing connexion with valued social relationships. Social policy which neglects the basic elements of social life and relies upon service intervention is costly and counterproductive. Policy should be designed to avoid the need for service intervention rather than to rely upon it. Service intervention, moreover, is no substitute for the psychosocial satisfaction derived from spontaneous relationships within family and community life.

3. Informal care

3.1 Terminology: general

The "rediscovery" of the elderly in recent years has also led to the rediscovery and reformulation of traditional concepts of care. Self-care, family care and lay or voluntary care, previously taken for granted or even derided, have assumed a new significance and produced their governmental, professional and popular apostles. Concepts and terminology are ambiguous, and the same terms are frequently used to denote quite different phenomena. In this report, we use "self-care" to denote activities conducted by the individual upon his own behalf; "self" is therefore used in its strict sense. "Informal care" is defined to include self-care and those caring functions carried out by family, friends, neighbours, volunteers and voluntary organizations. It is also intended to include care given by all individuals and groups other than those which are professionally trained, organized and paid to provide care.

3.2 Self-care, self-diagnosis and self-treatment

Self-care has a broad connotation. On the one hand, it must include all those activities which adult persons perform in order to live independently: personal bodily functions, housekeeping, budgeting, mobility and daily social relationships. In recent times, however, the

term has acquired other meanings more closely focused on health-related behaviour. One dimension relates to healthy living and the avoidance of behaviour likely to endanger physical and psychological health, e.g. poor nutrition, behaviourally-induced disease and social isolation. The specific meaning of these health precepts to the daily life of the elderly, insofar as the latter differ from younger age groups, seems to require better definition and description. Yet another dimension relates to the identification of illness, self-diagnosis and self-treatment. The perception and identification of illness by the individual (often in discussion with or in response to stimuli from other lay people) has long been recognized as the typical precursor of self-referral for treatment. Self-diagnosis and self-treatment, however, except in relation to minor and common illnesses, raise more controversial questions, particularly with regard to certain groups of elderly persons who are unfamiliar with the significance of symptoms and the availability of effective treatment or who may already be insecure and confused. Certain forms of self-care, especially in relation to common illnesses and to disease-preventive behaviour, are clearly economic and beneficial, and their discontinuance would place an unbearable strain upon formal services. More widespread and effective health education, especially at younger ages, can only produce good results. However, the application by the elderly population of precepts of self-care involving diagnosis and treatment requires careful and selective evaluation. Self-care should not be elevated into an ideology; nor should it be seen as an alternative to, or a substitute for, informed medical care.

3.3 Entry from informal into formal care system

The organization of formal health and social services is frequently complex and subject to bureaucratic rules and professional procedures. Even when crystal clear to service providers, its form and its entry points are often unclear to potential clients. Self-care, and especially preventive self-referral, would be facilitated if all possible attempts were made, through personal counselling, advisory services and information dissemination, to make elderly persons familiar with and confident about the options available to them and to their families and friends.

3.4 Family roles: reality and myths

A further and highly important dimension of informal care is centred on the family. Family patterns are changing, the extended family living in the same house or street is becoming less common, and women, the traditional providers of care, are assuming new responsibilities outside the family. The aging of the elderly population inevitably means that their children are themselves more likely to be elderly. Nevertheless, evidence from all parts of the European Region demonstrates that the major, most immediate and most continuous support of the elderly comes from their relatives. Not only do they frequently supply material support and housing, they also give personal bodily care not readily available from friends and neighbours and, through their mere existence, a sense of personal psychological security. They are frequently the go-betweens for the elderly in their contacts with organized health and social services. Their contribution is so important that a major objective of the formal services should be to provide support to family members in their continuing care of their elderly relatives - although research findings frequently suggest a tendency for formal services to supplant rather than to support.

Many supportive arrangements have been evolved in Member States. Universal approval from the elderly themselves and from family members exists for support given by home helps and domiciliary nurses, who perform the double function of carrying out burdensome tasks and reducing loneliness. Sheltered housing in the local community allows relatives to conduct normal lives, relieves their anxiety and lets them interact socially on a basis of equality. The extension of such schemes, already widely and positively evaluated, is to be commended. Other arrangements include the temporary accommodation of elderly persons in residential homes to provide relatives with a rest and the chance of a holiday; research findings suggest that the availability of such arrangements reduces pressure from families for the permanent institutionalization of their elderly relatives. Further experiments involve the payment of allowances to principal supporters to compensate for their loss of earnings and the granting of temporary paid leave at moments of crisis.

Families face two particularly stressful situations: the management of confused elderly persons and the confrontation of death - now frequently a process prolonged by advanced medical treatment. The management of dementia and dying involves physical strain, but, above all, anxiety and grief. The supportive intervention of services, using all the methods described above, is especially necessary at these times. Most old people prefer to remain at home as long as possible and, when given the opportunity, most would prefer to die at home. Even health professionals who meet death frequently have difficulty in coping with the stress involved, and more advice should be available to both lay and professional persons about how to manage it humanely and without unnecessary emotional stress.

It is, however, easy to idealize and romanticize the family as a source of continuing physical care and emotional concern. Many old people do not have living relatives, and some are distantly removed from them both in time and in relationships. Reliance upon the family by service providers must, therefore, be selective and provision must be made for those who are alone. Too heavy a reliance upon the family can, moreover, create its own problems. Many relatives are not only too far away to help, but they may also have pressing responsibilities to other immediate kin. A moral doctrine of family responsibility can create a burden of guilt, and some research findings document movingly the dilemma experienced by concerned relatives who are unable to undertake the responsibility.

The burden of care has traditionally rested, and still rests today, mainly upon female members of the family, who sometimes sacrifice their time, their social relationships and their careers to support their parents. Family relationships are not always benevolent: some relatives have quarrelled years ago, some resent the responsibility, and reports are beginning to appear of the abuse of elderly relatives, somewhat akin to the relatively recent recognition of child abuse. The prevalence, causes and implications of such abuse require examination.

These qualifications about the nature of family relationships are not intended to devalue the actual and potential contribution of the family to the continuing care of the elderly, but to avoid the excessive and uncritical use of the family as a convenient alternative. The idea of family and community care has been embraced with rather sudden enthusiasm by some governmental and professional agencies and has provoked suspicion that it may have economic rather than soundly-based care motivations. The family should be seen as one very important component of a network of concern and care and not as a cheap alternative to formal collective arrangements.

3.5 Neighbours, friends, volunteers

Informal care extends beyond the family to neighbours, friends and voluntary services. The relationship between these sources of care and formal services requires delicate handling. Neighbourhood and community are vague concepts, infused with warmth of feeling. Traditional relationships still exist in many parts of the European Region and particularly in rural or stable areas of residence. The modern urban world, however, is characterized by mobility, anonymity and relationships based on criteria other than propinquity. Extreme instances exist (and are increasing) of geographical communities composed of temporary migrants or of areas whose population is increasingly composed of elderly people. Service organization and practice need to be flexible and based upon reliable information about community characteristics.

Despite these cautions, neighbourhood and community care exist and make substantial contributions to the support of elderly residents. Neighbouring tends to be a spontaneous relationship dependent upon the ecology of the area and upon chance phenomena. Where it exists, it provides a range of services: surveillance, shopping, transport, social visiting and at times, but not frequently in urban areas, more personal forms of care. Again, reciprocity is an important element, and research findings often suggest that elderly people like to think that they, too, are providing a neighbourly service.

It is still unclear how far neighbouring can be stimulated by external social intervention or how far the provision of formal help causes a withdrawal of neighbourly services. More knowledge is required and some synthesis of existing research findings would be useful. What is clear is that the most sensitive work with neighbours must come from primary services, with their knowledge of community relationships. They can also be most helpful in ensuring that the network of supportive relationships does not disintegrate when elderly people move temporarily into hospital or other residential accommodation.

The role of voluntary agencies differs in one important respect from that of families and neighbours. While based upon concern, it does not spring from existing personal relationships. Voluntary agencies are perhaps best regarded as formal community organizations whose knowledge of local conditions and whose flexibility makes them valuable intermediaries between lay and professional care. Where formal services do not exist, voluntary services sometimes fill the gap by providing a mixture of professional and volunteer help. They are sources of identification and referral. In other contexts, they carry out experimental work, particularly in mobilizing unused resources. In some areas of the European Region, they act as pressure groups or as research agencies at local level. In all these capacities, they form an integral part of the network of concern and care.

4. Formal care

Formal services, conventionally subdivided into primary, secondary and tertiary services, in their scope, composition and organization inevitably reflect a variety of historical, cultural and political influences. Each national system consequently has its own peculiar identity and integrity. Lessons can be learnt from cross-cultural study, but it is usually unrealistic to expect that features of one system can be transposed to another without radical modification. Change tends to be incremental, growing out of the existing structure in response to local needs and constraints. Ideal systems thought out at the international level are, therefore, best regarded as long-term objectives rather than realistic immediate alternatives.

4.1 Common features among countries: deficiencies, constraints

Formal services in the countries represented in the Working Group do, however, share common features. The structure and the operation of services tend to reflect the ideology and interests of the professions and groups involved in the provision of care more clearly than they reflect the holistic needs of clients. Over several decades, in response to changes in need, but also in technology and specialization, new professions have arisen, each of which in its training and its professional organization emphasizes its distinctive contribution and its separate identity. Sometimes, and this is particularly true of the health and social services, professional separatism is embodied in separate organizations, each with its own clientele, its own criteria for admission into treatment or service and its own budget and accounting procedures. This creates confusion for clients, gaps between services and barriers in the pathways from one service to another.

One common phenomenon related to organizational and professional separatism is the "blocked bed" - the continued occupation of a hospital place by a patient who no longer requires hospital treatment but for whom no other suitable caring arrangement can be found. This is a complex problem, possibly reflecting the maldistribution of hospital beds between geriatric and other patients, but the phenomenon is more general, affecting movement between all levels of care from private homes through sheltered housing to residential homes, hospitals, psychiatric facilities and long-stay institutions. Ideally, the patient should be able to move from any one of these facilities to any other in response to his needs, but he is prevented from so doing by the general shortage of resources and by the organizational and professional separatism characteristic of the system.

Another common problem is the so-called social admission, that is, the admission of a patient to a residential institution when his needs could best be met in the community, the admission being the result of a breakdown in family and/or housing arrangements rather than illness. Such admissions may also reflect a combination of inadequate assessment procedures and of relative ignorance by one professional about the resources available in the community or about the potential contribution of other care givers. Such lack of knowledge and lack of contact between relevant service providers may also be a factor in the long period of stay in blocked beds, mentioned earlier. Procedures for the assessment of need and decisions about the management of care too frequently involve a single professional rather than the range of available and relevant skills and knowledge.

The standards of care existing in many residential institutions (and especially in long-stay hospitals) are recognized to be at an unacceptable level compared with those available to most other patient groups. This severely affects the morale of staff working in such institutions and has a depressing effect upon recruitment. This is manifested in many countries in the reluctance of native professionals to enter geriatric care and the consequent employment of a high proportion of foreign-born and temporary staff at all levels. Such staff are unlikely to be fully familiar with the beliefs, habits or even the language of the elderly people for whom they care, and this is not reassuring to persons already anxious about their health and their relative powerlessness. Poor recruitment and standards reflect the past and present under-financing of geriatric care, its partial separation from other parts of the health system and the ineffective and inefficient use of resources and manpower. Frail or confused patients frequently need more nursing than medical care and need to be less subject to the administrative routines characteristic of hospital systems. The imaginative involvement of family members in residential and hospital care would be facilitated by decentralization, so that patients were accommodated closer to their home community.

It was noted earlier that lay helpers were fearful of dementia and death. These conditions are also stressful to professional staff at primary, secondary and tertiary levels, and it is considered that more advice and experience in the handling of dementia and dying is required in the training of all health personnel. Such experience is being gained in some countries, in relation to dying, through the growth of the hospice movement, and attempts should be made to share this experience with other health workers throughout the system.

4.2 Innovative approaches

Countries throughout the European Region have developed an impressive array of services and helping professions, but elderly people still often lack information relevant to their health and are unaware of the range of options potentially available to them or of the means by which they can obtain service. There is an immediate need for better methods of providing the elderly with factual information, practical advice and counselling. Countries should consider how far improvements could be made through the greater use of local clinics and centres as advice agencies, through making professionals themselves better aware of the range of services, by cooperation with the mass media and by mobilizing the information and experience possessed by the elderly themselves for the benefit of their peers.

The rapid development of services for the elderly has produced many service innovations, notably at the intermediate level of care. Some are specific to one country or to a general system of services. Others are potentially generalizable to other contexts because they have evolved to meet common problems. The day hospital and its many variations is an obvious example. The Working Group felt that insufficient was generally known about these innovations and that, while some had yet to be evaluated, a knowledge of such developments elsewhere would be valuable for planning and administration. WHO would be in a good position to identify and collate such information.

5. Integration of informal, primary and institutional care

A recurrent theme of the Working Group and of this report has been the necessity to provide a comprehensive service capable of meeting the heterogeneous and changing needs of elderly people and to ensure an easy entry into and smooth transition between different modes of care. This concern has not been prompted by the desire to conform to such general principles as those promulgated by WHO in the Declaration of Alma-Ata, but by the recognition, based upon experience across the European Region, that elderly people are confused by and suffer from the artificial barriers created by compartmentalized thought, training and services.

5.1 Structure of services

Some countries have modified their formal organizational structure to create a more cohesive system, and much scope certainly exists for decentralization to local level, for ensuring that administrative boundaries are coterminous, for the merging of certain health and social service authorities and their budgets, for the diversification of facilities within particular institutions and for the development of intermediate services such as sheltered houses, community home help and nursing services, community service and day centres, day hospitals and outpatient facilities.

The structure of services, however, is of greater significance than buildings, and some organizational experiments have disappointing results unless accompanied by more resources, the reduction of bureaucratic procedures and the sensitization of staff to the potential contribution of the lay sector and of other service providers outside their own subsystem.

5.2 Team approach

Some countries have been able to operationalize the health team approach at the primary health care level. This typically involves the use of small but comprehensive teams containing persons with medical, nursing, educational and social service skills who work closely together, aware of and making use of each other's skills and communicating and cooperating in the identification, management and referral of cases. Such teamwork, within primary care, between primary care and institutional care, and between health and social services, is a highly desirable goal. At the very least, it can avoid the multiple, and possibly confusing and contradictory, management of an individual's problems by many service providers working in ignorance of each other's intervention. A well organized team approach can also ensure that, at whatever point in the system an individual presents for help, all available resources can be mobilized, either through cross-referral or joint action.

At the organizational level, this means that facilities can be planned and operated in such a way that the needs can be met flexibly, by the informal subordination of professional procedures and administrative criteria for eligibility to the particular requirements of the individual. Each health and social service system, however, has evolved historically out of past pressures and decisions, and it is unrealistic to expect that a common health team arrangement can be adopted and superimposed upon, or substituted for, existing national arrangements. The underlying principles must be cooperation and coordination, but the organizational form in which such principles are embodied must vary according to local conditions. Each country must start from its existing system, identify the barriers to cooperation and coordination, and then modify the system in accordance with both long-term goals and local service patterns.

5.2.1 Constraints in team-work: implications to health

One important barrier has been referred to earlier in this report, namely, the tendency of professions and organizations to develop perspectives, methods and operating rules in conformity to their own need for effective practice, without feeling similar pressures to ensure smooth working relationships with other professions and organizations. The Working Group considered two special facets of this separatist tendency. On the one hand, they asked how much cooperation could be expected in practice when professional education was conducted in isolation. Clearly, it was impracticable to suggest that all professionals should have a common training. Examples were cited, however, in which medical students, nurses and social workers came together at certain stages of their training to be instructed in and to discuss particular problems of common concern. Experiments in limited common training, properly evaluated, might indicate how far earlier awareness of mutual problems and of different methods of handling such problems changed attitudes or had an impact upon later professional behaviour in terms of consultation or cross-referral.

A second facet was the potential effect of different methods of remuneration. It seemed possible that certain types of professional remuneration for services rendered, and in particular fee-for-service methods, might reduce cooperation, particularly in matters of continuing care. This is part of a wider question of how the working conditions, lines of authority and communication and degrees of autonomy in decision making differ between professions in ways which might impede flexible cooperation between them.

Health, in the broad sense of "physical, mental and social well-being" incorporated in WHO's definition,^a extends well beyond the provision of services and beyond actual sickness. The welfare of old people is affected by policies and decisions taken outside the formal health sphere but which impinge upon fundamental aspects of living. We are thinking here about policies concerning the age of retirement and the right to work beyond the official retirement age, the level of and eligibility for social security pensions and other financial benefits, the availability and costs of suitable types of housing or of housing modification, the costs of travel and the accessibility of leisure facilities.

5.3 Role of traditional medicine

Many religious and secular groups are offering a healing or a helping service to sick or elderly populations in countries of the Region. The elderly make substantial use of such unofficial healers and experts. In general, the official healing and caring professions have tended to frown upon the activities of lay healers and carers and have made little attempt to inform themselves about their potential contribution. Since they are being widely used, it seems unwise to ignore and ostracize them on principle. On the contrary, the potential contribution of lay healers and carers towards meeting the needs of the elderly should be carefully examined and consideration given to the role they might play and to their relationship with the formal system of care.

6. Information and research

6.1 Gaps

Many gaps exist in our understanding of the problems of aging and of the elderly and in our information about the effectiveness of existing and alternative modes and patterns of care. Understanding and information must, moreover, be continuously updated if they are to reflect changing needs and provision and to incorporate new ideas and developments. There should, therefore, be no lessening of the flow of information and research. Careful consideration now needs to be given, however, to the kind of knowledge needed for the better planning and provision of services and their relationship to informal systems of care.

6.2 Role of surveys

There has perhaps been an overemphasis upon the more easily conducted general surveys of the characteristics and needs of the elderly, the results of which provide a general informational background but which are difficult to translate into service organization. The Working Group attached importance to periodic national and local surveys of the elderly and their problems and to the continuous improvement of information systems. Such surveys and systems, however, are of limited applicability unless they are designed to answer specific questions. Much of the information available to practitioners and planners comes from persons who are already in contact with the service. The more general survey provides an opportunity to identify those not in receipt of service and thus, on the one hand, to estimate the nature and extent of unmet needs and, on the

^a Constitution of the World Health Organization

other, to explore those personal, familial and environmental situations which are sufficiently supportive to render the use of formal services redundant. This topic, however, is so important in its relevance to the possible contribution of informal care and, at the same time, so complex that it requires greater depth of study than the survey method alone can yield.

6.3 Priority topics for research

- (1) The degree to which elderly persons either have the abilities to practise or do practise various forms of self-care.
- (2) The roles played by principal supporters and others in the support and care of elderly persons and the impact of their roles upon the lives of such supporters.
- (3) Elderly persons' perceptions of their needs and their subjective evaluation of services.
- (4) Ecological studies in which interrelationships can be established between the situations and needs of the population, standards of living, systems of informal and formal care and elderly persons' perceptions of the quality of care and its relevance to their needs; such studies are urgently needed in many rapidly changing urban areas of Europe and particularly in areas of high immigration.
- (5) The services themselves, so as to identify organizational problems, to analyse the source of such problems and to explore alternative solutions.
- (6) There should be more widespread use of evaluative research as applied not only to organizational change but also to ongoing services, in which formal objectives would be compared with various criteria of performance including the judgment of clients.
- (7) More work is needed on cost-effectiveness, particularly at the level of primary prevention, so-called community care and custodial care. It seems likely that particular methods of paying professionals for their work and of funding basic services affect the balance of prevention, cure and care and also the nature and degree of collegial cooperation between professions and services.
- (8) Methods of funding prevention and long-term primary care in insurance-based or fee-for-service systems required examination.

6.4 General remarks on research

The emphasis of research should be shifted towards the study of services in action, including evaluation, and away from broad epidemiological and social surveys. Particular importance should be attached to the study of experimental schemes, often at the local level, through which administrators and practitioners have adapted formal systems to reduce disjunction between services, to improve communication and to make services accessible and relevant to potential clients. The volume of such innovation is considerable, and much may be learnt by the collation and analysis of existing material and its dissemination to policy makers, administrators and professionals. Considerable benefits could be gained from the careful synthesis of existing knowledge derived from research already carried out; in this connexion, it might be more cost-effective for WHO to carry out or commission comprehensive reviews rather than conduct original research.

7. Recommendations

- (1) To achieve continuity of care, the following general principles should guide policy, administration and practice:
 - (a) the informal system of care is invaluable in its own right and should not be regarded as a substitute for formal services;
 - (b) a prime objective of policy and practice should be to support the informal system so that its contribution can be maximized;
 - (c) formal and informal systems should be interwoven, not only at the primary level but at all levels of care, and those working in each system should be educated to make the best use of the services and resources of the other;
 - (d) the goal of policy should be to ensure an integrated system of informal and formal care which can respond to the needs of the individual and in which elderly persons can locate appropriate services with maximum flexibility of interchange between organizations and types of service;

(e) adequate standards of living (in terms of food, housing, income, security, mobility, leisure and work) are an essential prerequisite of continuing wellbeing and independence; the principle of integration requires that policy and practice should take this fully into account in the planning of a comprehensive service;

(f) relationships between the services and elderly persons should be based on the principle of reciprocity, elderly persons being involved in the planning of services and being called upon, where appropriate, to provide help for others.

(2) Positive action is required to break down the barriers between professions and organizations in the provision of an integrated system responsive to individual needs. Experiments in joint professional training should be encouraged and evaluated.

(3) Many innovations in relation to the integration of formal and informal care systems are currently being conducted in the European Region. WHO should take steps to document and evaluate such innovations, to disseminate knowledge about them and to arrange for their discussion by a wide range of organizations and professions.

(4) Since lay and professional persons encounter extremely difficult problems in the acceptance and management of dementia and dying, WHO should consider what steps it might take to improve methods of managing these difficult issues and to disseminate such methods.

(5) The low standards of care which still exist in many geriatric institutions are both morally unacceptable and a deterrent to good staff recruitment. WHO should consider means of reviewing this problem.

(6) The emphasis of research should move away from broad epidemiological and social surveys towards the study of the services in action. Work is especially required on factors facilitating or impeding the integration within and between primary and secondary levels of care and between formal and informal systems.

(7) More carefully defined and designed research is required into the various components of informal care (self-care, family care and other lay care), its potentialities and limitations and its subjective evaluation by elderly persons and by principal supporters.

(8) Considerable benefit can be derived from the careful synthesis of past and current research, much of which is unknown outside national boundaries. WHO, by virtue of its central position, should examine the possibility of undertaking such research synthesis.

Annex

LIST OF PARTICIPANTS

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^a Participation expenses not paid by WHO

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