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Home Care in the Americas: Issues Related to Organization and Management

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PRESENTATION

The work of the Pan American Health Organization (PAHO) on home care began in 1998 as an interprogrammatic activity between the Organization and Management of Health Systems and Services (HSO) and the Program on Non-communicable diseases (HCN) on palliative care for clients with cancer. As the work progressed, it became clear that the need for home care for individuals and their families was also a challenge. Thus, we have taken the initiative to explore Home Care in the Region of the Americas and to focus initially on the feasibility of developing home care services in countries without home care and the refinement of services in areas where home care programs already exist. With some exceptions, anecdotal information suggests that organized systems of home care are not generally operating in developing countries. There are several notable exceptions: one exception is programs developed to care for clients with a particular diagnosis (usually cancer or AIDS) and which use volunteers rather than paid staff, primarily through a non-governmental organization (NGO). A second exception is programs associated with prepaid or managed care insurance schemes, such as CASMU in Uruguay. Of note, a number of trials in developing home care schemes have failed due to financing problems.

All home care programs must undergo their own unique development in response to individual and community needs and within a health system and political context. The diversity of home care programs is both a strength and a weakness in development in this sector⁽¹⁾. While individual programs allow for specific and local responses to address needs, the lack of common terminology, standards for service delivery, and information gathering has kept individual programs from benefiting from the development of collective initiatives, including research activities, analysis of the cost-effectiveness of interventions, and information systems to support improved management and policy-making.⁽¹⁾

There is considerable variation among home care programs in different countries and in different regions within a country, (e.g. in rural and urban areas of developed countries). Much can be learned from the experiences of developed countries, especially now with a relative period of increase in demand, growth and reform in this area compared to other sectors of the health system. Lacking are systems to support the collection and dissemination of information to support evidence-based decision-making at the local, regional, national, and international level.

The purpose of this paper is to present an overview of the issues in the organization and management of home care services which can then be used to help in developing or refining home care

service delivery specific to the needs and demands of each population. The topics to be addressed include: trends supporting the need for home care services, principles and values inherent in the provision of home care services, concepts and definitions of home care, models of service delivery, the organization of home care programs, caregiver issues, financing, quality issues, and the challenges presented.

A review of Spanish language databases and inquiries to key informants in Latin American countries provided preliminary information about programs in these countries. This paper is based on literature reviews, information from key informants, and the collective efforts of an ad hoc group which met in November, 1999 with an update of the literature in fall 2002. It addresses some of the problems surrounding definitions of home care and provides a conceptual model that recognizes that home care should be at the center of a network of health services at all level of care--primary, secondary, and tertiary.

1. INTRODUCTION

The Region of the Americas, with a population of approximately 800 million, accounts for 13.5% of the world's population and has achieved much by way of improvement in the health status of its peoples. With growing awareness of the influence of the broad determinants of health, health care has moved beyond the recognition of biological and behavioral causes of illness and diseases. PAHO has seized the opportunity to address health services in settings other than health care institutions. PAHO also recommends that home care, as a modality of health care, should be viewed as an equal alternative or complement to institutional care. In light of the ongoing health sector reform process, this is an opportune time to incorporate home care as an integral part of each country's health care system. The bases for considering home care as a viable alternative are mainly epidemiological, demographic, technological, economic and social in nature. Each country within the Region must consider these factors in health services planning and development.

1.1 EPIDEMIOLOGIC TRENDS

Disease patterns are changing. While countries are still grappling with communicable diseases, the effect of the rising incidence of chronic diseases is evident. A significant number of communicable diseases are chronic and will require long term care. These diseases include HIV/AIDS, Tuberculosis and malaria.

1.2 DEMOGRAPHIC TRENDS

The major demographic trends, including morbidity and mortality changes throughout the Region, point to an aging population with concomitant increases in chronic diseases and complications associated with the end of life. It is estimated that 10% of the population of the Region will be 60 years or older by the year 2000, mainly attributed to an increase in life expectancy increases. This indicates that national policymakers in all countries must design programs to support the significantly higher number of elderly in the coming decades. In light of the changing family structure and consequent decline in the family support available to the elderly in many countries in the Region, it is essential to explore formal and informal service availability to ensure adequate care in the home. There is a case to be made for a system of community-based long term care in all the countries of the Americas.

Each country has issues relating to:

- The steady increase in life expectancy to an average of over 60 years in the Region.
- The continued challenges of some chronic communicable diseases i.e. HIV/AIDS, tuberculosis
- The increasing prevalence of chronic diseases such as heart disease, cancers, renal failure, cerebrovascular deficiencies, and diabetes
- The prevalence of dementias in developed countries
- An increase in trauma and injury (intentional and unintentional), which frequently result in long term hospital stays and the need for rehabilitation.
- Maternal and child care —maintenance and improvement in achievements in maternal and infant morbidity and mortality
- Childhood developmental challenges resulting in the need for continued long term care

1.3 TECHNOLOGIC TRENDS

In some countries technological advances make it possible to transfer some procedures from the hospital setting to the home. Examples include: peritoneal dialysis, oral rehydration, intravenous therapy and mechanical ventilation. Even in countries where such technologies do not exist, there is the need and potential for home care interventions to take on some of the modalities previously restricted to institutional/hospital care.

1.4 ECONOMIC TRENDS

From an economic standpoint, the need to control the ever rising cost of health care, coupled with the current cutback in health budgets, points to the necessity for serious consideration of home care as an important and viable modality of health care delivery. Early discharge and outpatient day surgery has been used as a way of controlling hospital expenditures. This already has been applied in the case of home deliveries or early discharge of mothers and their newborns from hospitals and then cared for through a system of follow up at home. Health promotion and primary prevention in the home has already been shown to be efficacious in many developing countries where home visiting is a part of the primary health care system.

1.5 SOCIAL TRENDS

Finally, in many cases, provided that adequate instruction is given, the family setting remains the most appropriate and effective place for recovery and health maintenance or, should it come to that, a dignified death. The sociological, socio-cultural and spiritual aspects of care given in a family setting are major advantages for the recovery and/or the maintenance of health or a dignified death. Various studies in the developed world have demonstrated that in nearly all cases, home care significantly increases the satisfaction of clients, families, and health providers. In developing world countries, on the other hand, hospitals can be seen as places of refuge when illness or injury occur; hospitals provide shelter, regular meals and health care providers, all of which may not be as readily available to those who live in poverty stricken or remote areas.

Conceptually, from a continuum of care perspective, some aspect of any disease/condition can be addressed in the home setting; no disease/condition precludes the delivery of services in the home at some point in the trajectory of health care.

It is evident that as we enter the third millennium the goal of Health For All remains a distant, yet worthy objective. The challenge is to recognize and address the impact of the various determinants of health. With respect to the health care system, changes should be targeted to increase the accessibility and equity throughout the Region. The opportunity exists for health care providers to develop new models of care to bring about these changes.

The intention, therefore, of this report is to bring to the fore the issues which, in the 21st century, need to be addressed as the paradigms of health care delivery shift to embrace a mix of the traditional along with new technologies.

The values that underlie the development and provision of home care are congruent with those of the larger health care system. At the same time, these values reflect the unique characteristics of home care.

Principles related to the development and implementation of home care may include:

- Care is provided to all who require it without discrimination; cultural differences are respected and valued.
- Care is centered on the needs of individuals and their families. Where possible, there is some flexibility to provide a range of choices to address varying needs, living situations and commitments of the family and the health care providers.
- Home care takes place within a wider health and community (social) context. It promotes/supports an integrated approach to services, thus maximizing limited resources, but observing the ethical principles and standards governing the delivery of health care.
- The objectives of the home care program and the anticipated outcomes are well defined and communicated to stakeholders/public.
- Family caregivers are valued, respected and supported. Home care services do not seek to replace this normal level of care giving nor does it impose an unfair burden on family caregivers.
- The contribution of health care providers is valued, respected and acknowledged with adequate support, resources and education/training.
- Independent living is supported. The most natural place for individuals and their families is at home in their community.
- A well identified centralized system exists for the purpose of setting overall policy guidelines for service delivery with a mechanism for setting quality standards.

3. CONCEPTS AND DEFINITIONS

Due to the diversity, range, and orientation of services among programs, differences exist within and among countries. Home care programs with an acute care orientation are defined differently from those incorporating a broader range of services required to manage chronic conditions and disabilities. The scope and definition of home care must be broadened to recognize that home care needs to be built on innovative approaches that take into account the sociopolitical contexts within each country. While acknowledging the diversity and range of programs, it is also essential to standardize the definition of terms in the interest of attaining a common understanding and developing structures capable of providing home care as a component of the health care system. A clear-cut presentation of such terms provides a common language.

There are many reasons for visits to the home by health professionals. A valuable framework is the primary, secondary and tertiary levels of care used in the public health literature. The primary level of care is concerned with prevention of disease and promotion of health. The secondary level of care comprises the acute phase of an illness or injury, while the tertiary phase is concerned with the recuperative or rehabilitative level of disease. (Note that this is distinct from primary, secondary and tertiary levels of prevention that occur within all three levels of care.) Examples from PAHO countries:

Primary level of care: In Chile, home visits are made by community health nurses or community health aides to follow up with infants who have not returned to the well child clinic for immunizations. The nurse or the aide provides client education about the importance of the immunization and makes the follow-up appointment.

Secondary level of care: In Jamaica, home visits are made by nurses employed by an NGO to clients with insulin dependent diabetes for the administration of the insulin. Primary care visits in the home are given by staff in government services.

Tertiary level of care: In the U. S., a multidisciplinary team (nurses, physical therapists, occupational therapists, speech therapists and home care aides) are used to provide home care to clients who have had a stroke with hemiplegia and aphasia.

Some countries may combine more than one level of care: In Canada, the public home care program responds equally to secondary (acute care) and tertiary (long-term/chronic care).

In addition, there are other definitions that may be helpful in explicating the similarities and differences in the definitions of home care. Three that may be of use are home care, home visits, and home procedures. In the process of development of this document, we realized that our own individual definitions of home care made it difficult for us to understand how other types of home care were really “home care”. Thus, our goal was to be inclusive of the various types of home care provided in the PAHO Region.

3.1 HOME CARE

In its broadest sense and for the purposes of this document, home care is defined as the provision of health care services in the home. This could encompass a holistic, comprehensive program of coordinated care provided by a multidisciplinary team or it could be as simple as providing a single home visit to perform a specific procedure.

Comprehensive home care is the coordinated provision of health care in the home that delivers a certain number of services of varying duration and complexity and that enable the beneficiary of care to remain in the family environment under the best possible conditions.⁽²⁾ Another definition identifies home care as a formal support network. These services include both health professionals and other community support networks (public, private, and volunteer). Comprehensive home care implies holistic delivery of care, which may include physical care, treatment/clinical procedures, personal care, the training of health care providers (family or neighbors), social and psychological support of the client and family, orientation with regard to social and financial benefits, and referral to other services and professionals, as needed.⁽²⁾

The objectives of home care are:

1. Prevention of health problems, whenever possible
2. Management of and interventions with existing acute problems
3. Management of and interventions with chronic health problems

3.2 HOME VISITS

Home visits could include visits to the client’s home by one or more members of the health team. This is separate and distinct from the comprehensive home care program described above. They usually form part of the program priorities of the health services at the primary care level and are also a component of the socioeconomic

and demographic care/assessment of a family or household. To clarify, although a comprehensive home care program involves visits to the home by health care providers, the home visits discussed in this section include only isolated home visits made for a purpose apart from comprehensive home care.

In some countries, (Canada and probably others) this type of visit takes place in the context of public health programs or there may be a devolution of services from public health to home care where such programs are no longer offered. For example public health nurses provide home care visits to ensure clients with tuberculosis are taking their medication.

3.3 HOME PROCEDURES

Home procedures are intended to address the specific diagnosis of a health problem. Health interventions conducted within the framework of home care focus on the solution of specific health problems through specific health activities or interventions usually carried out by a member of the health team. Home care is usually described as “intermittent” care provided in the home. If this care is part of a home care program or plan that is coordinated with other home interventions and employs a holistic approach, then comprehensive home care and home procedures can be defined as equal and, hence, interchangeable terms.

These three concepts have been selected as those mentioned most frequently in the literature. Consequently, this sample does not seek to diminish the value of other definitions or terms in use nor to limit the emergence of new concepts and definitions that may result in further development of this kind of care.

4. MODELS OF SERVICE DELIVERY FOR HOME CARE

Health care services in many parts of the Americas are in the process of being developed, reformed, and reorganized. (For more detail, the reader is referred to Health Sector Reform Initiative for Latin America and the Caribbean.)

In some countries, home care programs may be one way to further develop or modernize the health care system. Home care programs may be coordinated systems for home and community health-related services that enable people to live in their home environment and to achieve their optimal functional capacity. Improving communication and service coordination with other parts of the health care system needs to be strengthened in order to provide effective linkages with home care in those countries where home care programs exist. A smooth transition from hospital to community and home care and vice versa can only take place in an integrated delivery system.^(1,3-6)

Differences in cultural, physical, and socioeconomic environments make it impossible to promote a single approach in the delivery of home care services; rather, it is important to identify a range of effective models rather than focus on a single service delivery model.^(5,7) The goal of home care is to promote self-care capabilities in the client's home while ensuring cost effective care appropriate for the client's condition. Elements for a comprehensive model for home care include: concepts of health service delivery, and standards of care on which to focus practice and which guide the development of caregiver interventions that are cost efficient and effective.^(5-6,8,9) The model should also include the capability to measure the quality of services delivered in the home and the outcomes of this care. Specifically, each program should strive to document client outcomes as a result of home care services and information on which level of provider results in improved outcomes, what mix of services is necessary for which vulnerable group, and which services are most cost effective. This data could be used to compare programs/services and to determine best-practice models.

Home care services can be categorized as either intermittent or continuous. Continuous services offer clients some level of hourly care, generally at least 8 hours of care per day, every day, but up to 24 hour care. This expensive model is being used under certain circumstances in both developing and developed countries. The services provided can range from primary levels of care to tertiary care, although the focus is mostly on secondary and tertiary levels of care. Intermittent models are the most common models worldwide.⁽¹⁰⁾

In Canada, a quick response team model is used for clients with an acute illness or injury who can be cared for in the home. A homemaker (type of home care aide) stays round the clock for up to seven straight days with the skilled intermittent care provided by nurses, physical therapists and other specialty providers.

Intermittent services may be staffed exclusively by trained nurses or by teams of nurses and doctors or a mix of professional (nurses) and non-professional (home support workers or home care aides). In both cases, in well established home care programs, there is usually access to social workers, occupational therapists, and physiotherapists who provide consultative assistance or direct care. In addition, there are some models that include both categories.

In Canada, all home care programs include a complement of home support services and case management. In addition, there is also a call system associated with some urban home care programs where unscheduled visits can be made in the event of an urgent health crisis.

In the U.S., the multidisciplinary approach is the most common approach, although nursing care predominates.

Another aspect of home care to consider is whether only scheduled, routine visits are made or whether there is the capability of response to an urgent health crisis, such as an AIDS client abandoned by family members and in need of home care services for the administration of intravenous antibiotics, fluids or nutritional requirements.

Comprehensive services can and should be designed to meet local needs and conditions. Primary and other local health care services should collaborate in planning comprehensive services. The tendency, without sufficient planning, is that there is service duplication.

In Ontario, Canada, a study of patients receiving home nursing care for leg ulcers found that 40% of the nurses' time was spent travelling from one home to another and that only 15% of the patients receiving care were actually housebound. Thus, 85% of the patients could have received nursing care in a clinic setting as compared to the expensive home visit modality (Frieberg, E. H., Harrison, M.B., & Graham, I. D. (2002) Current home care expenditures for persons with leg ulcers. J WOCN, 29, 4, pp. 186-192.

5. ORGANIZATION OF HOME CARE PROGRAMS

There are at least five steps to be taken in developing a home care program:

- First, there needs to be an identification of how health care delivery is evolving within each country and its strategic direction.
- Second, there needs to be a comprehensive approach which includes collaboration with relevant parties within the existing health care framework/structure within the country to plan, develop, and implement home care services.
- Third, identification of the various partners needs to be undertaken –these partners might include all levels of government, service providers, NGOs, church groups, universities, health insurance plans, consumers and others.
- Fourth, consideration needs to be given to the methods of financing.
- Finally, the current health care labor resources (supplies of physicians, nurses, auxiliary nurses, community health workers and so on) need to be considered.

Existing home care services are often fragmented among organizations providing acute and community care and between health and social agencies. Therefore, responsibility for services to clients is spread over many agencies, and no one party is really accountable or has the authority to transcend agencies.^(1,3,4) Governments have been encouraged to fund and facilitate home health care. However, there are profound philosophical differences between acute care institutions and community health agencies in the focus and purpose of care. Therefore, it is important to have a clear understanding of the mandate and objectives of all agencies involved. It is also important to establish who is accountable to the authorities for funding allocation and service delivery. Finally, it is also important to establish which authorities are accountable and responsible for the decisions around home care. As programs evolve, it would be useful to consider the benefits associated with comprehensive assessments of needs, a single point of entry to all programs/services within a region, and case management.

The transition from institutional care to home care must be planned, managed, and part of a comprehensive system of health

care. Moreover, since home care is multifaceted, the planning must be tailored to the particular parameters of the program as well as the circumstances of the individual client. It is therefore important to decide who will administer the home care programs, who will refer clients to receive home care services ⁽⁸⁾, and how all the players will be linked to form an orderly network to support home care.

Principles and guidelines, as previously presented, are required to promote equity in accessing this level of care. All government health care systems should confirm who sets overall policy guidelines and standards for service delivery, reporting requirements, and monitoring outcomes. Eventually, policies governing the delivery of home care services should be considered.⁽⁸⁾ Finally the quality, cost, and effectiveness of services should be monitored and evaluated in order to determine future strategies for ongoing improvement of the overall system.⁽¹¹⁻¹²⁾

The basic eligibility requirements for various components of home care services must be considered and communicated. All groups, especially vulnerable individuals, should have access to home care. Vulnerable groups, depending on the country, may include the elderly, clients dependent on special technology, the disabled, minority and indigenous groups, certain high-risk infants and children with complex medical problems, the poor, shut-ins, and those without anyone to care for them. All should be eligible for or have entitlement to receive affordable home care services. Eligibility includes: proof of residence; a needs assessment conducted prior to any service provided; care as a response to unmet needs; a safe home that is suitable for service delivery; and the consent of the client or his legal representative.⁽⁸⁾ Yet, not everyone in these groups may need the same full complement of services, the same level of intensity and duration, or services from the same type of provider. Therefore, the length of the service should vary with the specific needs of the client or group of clients. It is also important to consider whether there is equity between facility-based and home-based programs. Assuming home is the appropriate site of care, it is important to determine whether drugs, supplies, and equipment needs will be covered in an institutional setting but not if the client is receiving care at home.⁽¹³⁻¹⁴⁾ The principle of universal coverage should be extended, where possible, to home care and should be embraced by public and private funding agencies and health insurance companies. Finally, aside from eligibility criteria and selection conditions, it is critical for the client to be treated at the level or setting of care that is most appropriate for the condition/disease.

5.1 ORGANIZATIONAL STRUCTURE

The organizational structure of home care programs may be classified according to the origin or institution from which services or the kind of services that are provided. Common models found in the PAHO Region include the following:

- Community-based multisectoral programs. The interrelated organizations in this case include a broad spectrum that ranges from governmental and private health institutions to private insurers, including the informal or traditional sector—all of them centrally or locally coordinated or ad hoc. The inclusion of alternative or indigenous health resources represents both a need and a challenge for the delivery of home care.⁽²⁾
- The Catholic Church in Chile has developed a home care program, Hogar de Cristo, for anyone who cannot afford to pay for home care. The program provides nursing and physician care as well as community volunteers. There is some coordination with the health care system, especially with the hospital sector, although on an informal basis.
- In Uruguay, CASMU, a non-profit capitated program, provides home care as one of the services to 260,000 residents of Uruguay. Home care complements ambulatory services and hospital care. The home care is provided predominantly by physicians, nurses, auxiliary nurses, physical therapists, nutritionists, medical students, pharmacists, and administrative personnel. The home care is provided on the secondary and tertiary levels of care to mostly elderly people. There are four types of programs—internal medicine, pediatric, psychiatric, and palliative care. In a recent study, clients with a diagnosis of pneumonia represented more than half of the home care clients seen.
- In many countries, there are church-based programs that provide home assistance to members of the community. These programs are informal, are not coordinated with the larger health care system, and exist in an ad hoc manner.
- Programs associated with a hospital or publicly funded health institution: These programs are a response to a need perceived by both the community and the professionals of a service within the larger institution. They are limited to specific and specialized care, provided in a specific geographic area. They are usually not-for-profit initiatives, and their services are available to all who require them within the constraints of the program.⁽¹⁵⁾

- In the U. S., a relatively large proportion of home care programs, more than one third, are hospital based (i.e., part of the hospital system). While the organizations are hospital-based, the funding for the home care comes, in large part, from the federal and state government systems. Care is primarily provided to elders with specific requirements for health status and the ability to leave the home. The care is primarily focused on the secondary and tertiary level of care.
- Private programs: These are for-profit institutions that deliver home health care services, usually affordable only to the upper-income sectors. They may be associated administratively with a major health institution (hospital), also private, or operate independently. They usually cover a broader spectrum of care than those described above.
- In many countries of the Americas, a separate health sector exists for those who can afford to pay additional amounts beyond what is covered by publicly funded or employer-sponsored health insurance. This system allows for private hiring of help in the home or access to private home care programs.
- In Argentina, a pediatric home care program was started by pediatricians for neonates whose families and physicians agreed that home care was appropriate. The care is paid for by the families (Alvarez & Gril).

It is important to note, however, that these organizational structures are not exhaustive or mutually exclusive. For example, in Canada, there are three models of home care provided by the provincial government: maintenance and prevention model, the long term care substitution model, and the acute care substitution model with each province customizing additional services to meet regional needs (Sorochan, M. (1997). Home care in Canada, International Journal of Health Care Quality Assurance, 10, 4, pp. v - x.

5.2 LOCATION OF HOME CARE IN THE VARIOUS CARE PROGRAMS AND LEVELS:

Achieving universal access to home care is presently dependent on the recognition and development of firm support strategies for this type of care by government health care systems. Similarly, the recognized benefits of a home care system, such as a general reduction in health care costs, greater user and professional satisfaction, and greater effectiveness in the care provided, can only be achieved through appropriate integration of home care into the health systems, which in all cases implies coordination and

collaboration between the various health care components in the health services and the home care systems.

The model in Figure 1 is a graphic representation of the various systems and relations underlying home care. This model is based on the following assumptions and concepts:

- 1) The three levels of care that make up the health services systems are related to one another through referral and feedback system. These levels differ not only in their degree of specialization and coverage, but also in the various forms in which they relate to the community and in the strength of these relationships. It must be noted that most health care interventions, simple though they may be, occur in the home.
- 2) The coordination, collaboration, and interaction of the various levels of health care with one another and with a home care organization is essential for achieving the objectives and desired outcomes in a home care program. These kinds of relationships should be expressed to ensure at least that:
 - Preventive measures are taken in the home (e.g., investigation and education of household members regarding index cases of communicable diseases).
 - Client referral to available home care systems is adequate, appropriate and timely.
 - Education of clients and their families is timely and adequate and is a priority of the institution or professional who refers a client to a home care system. Ideally there should be some form of coordination between the two entities
 - Immediate care is available within both the institutional and the home care system, if a client needs to move quickly from one system to the other.
- 3) A home care program should be effective in terms of functions and costs. The system of coverage should make it possible for clients and their families to receive home care without incurring undue personal costs.
- 4) The community is the environment in which home care programs are developed, and consequently its support and active participation in the provision of these services is essential for meeting the health objectives. The community consists of the family (as the principal group closest to the client), other important persons, organized volunteer groups and support services for general

needs, such as hygiene, nutrition, transportation and social interaction.

Application of the principles of primary care will facilitate effective utilization of all the available and necessary community resources in each case, thereby optimizing the care delivered directly by the health team and imbuing it with a holistic approach.

TABLE 1. COMPARISON OF CHARACTERISTICS OF INSTITUTIONAL CARE AND HOME CARE

Characteristics	Institutional Care	Home Care
Place where the care is delivered	Clinic, hospital, nursing home, general polyclinic, general physician's or specialist's office	Home environment . Can include boarding homes, group homes and seniors residential facilities.
Persons who provide the care	Mainly health care professionals	Clients (self-care), mainly family members Health personnel (including professional and non-professional), community health personnel, volunteer health workers, support services
Influence on decision-making	Providers (health team)	Clients and family members (mainly)
Focus of care	Clients and their specific health problems, use of technology	Clients/family members' specific health problems Holistic care

TABLE 2. CONSIDERATIONS FOR THE INITIATION AND DEVELOPMENT OF HOME CARE SERVICES

Necessary Basic Questions	Responses and Results	
	Yes	No
Does collaboration, communication, interaction and coordination exist between the various health providers and home care services/program?	Delivery of appropriate, high quality and highly valuable care to users.	Disorientation of clients, families, and professionals. Gaps in health care at various levels including home care.
Is the education of clients and their families timely, relevant, and adequate?	Adequate and effective decision-making, acceptance and participation of clients, families, and the community.	Reduces participation and acceptance of the family in direct care and decision-making, which negatively influences health outcomes
Have the clients' and families' sociocultural, economic and psychological situation been taken into account, in addition to their environmental conditions, when proposing home care as a viable alternative?	Realistic objectives established jointly with clients and their families. Greater cooperation and commitment to health outcomes are obtained and self-care is promoted.	Feeling of failure and frustration expressed by clients and family members. Complications in the health of clients may arise or increase.
Is there adequate formal care (clinical and personal), technological and financial support for the kinds of clients who will be referred to home care?	It is possible to make appropriate decisions with regard to those who should and should not be referred to home care. Minimum outcomes in health and user satisfaction are ensured.	Clients and families reluctant to participate in the home care program as they feel a lack of support. Clients may unnecessarily need to go to a higher level of care (hospital or nursing home)
Has a proper assessment of the decision-making process within the family been carried out? Has a proper assessment of the ability of the health professionals with regard to a different	Adequate distribution of responsibilities and priorities in decision-making and promotion of consistency between decisions and functions.	Conflict of power and decision-making within the family and with health professionals.

Necessary Basic Questions	Responses and Results	
	Yes	No
role in decision making in home care been made?		
Are appropriately trained health care workers available for the delivery of home care?	Home care is a viable site for the delivery of health care. Appropriate development of skilled professionals.	High rate of prolonged hospitalizations and rehospitalizations and client/family dissatisfaction. Inappropriate level of interventions. Poor quality of care.

6. CAREGIVER ISSUES

Caregiver issues arise for both family/friend caregivers, referred to as informal caregivers, as well as for formal caregivers, who are members of the health care team.

6.1 INFORMAL CAREGIVERS

Family caregivers are a critical part of the multidisciplinary health care team, especially in the delivery of home care. They are a critically important part of the client's natural environment, contributing directly to their quality of life. Family members are estimated to provide as much as 75 to 80% of informal care to individuals who have long term health problems or disabilities.⁽¹⁶⁻¹⁷⁾ The care provided by families and friends includes a variety of tasks such as personal care, meal preparation, household support assistance with shopping and transportation, and complements the work of the formal (paid) health care workers.

Family caregivers also have their limitations and preferences that affect the type and amount of care that they can be expected to give. They have needs that arise directly out of their caregiving work. They may make personal and financial sacrifices to give care. Their own health and wellbeing may suffer as a consequence of the kind and amount of care they give.

Family members who are providing care may need support in the caring role, both to help them meet the needs of the person requiring care and to help them meet their personal care or family needs during the time they are caregivers. Caregiving can represent simultaneously a burden as well as a reward.

Home care programs can provide supports for family caregivers which may include: information, advice, training, service coordination, and respite care.

6.2 FORMAL CAREGIVERS

There are a variety of formal caregivers. In some countries, for example Canada and the U. S., nursing is the predominant professional provider of home care services. In countries where there is a relatively larger proportion of physicians, (e.g. Uruguay) physicians are the predominant providers of home care. In countries with a primary health care focus, community health workers are common providers. For all formal caregivers, there are common issues of working without immediate physical support from

other health care workers and working in isolation. Health care workers in some countries are well adapted by training and experience to working in the home and community, whereas in other countries orientation and training would be needed. Some of these differences may be due to a strong reliance or past experience with hospital level technology.

Educational programs vary widely in the preparation of formal caregivers for the provision of home care. In some areas where there is movement from a primary level of home care (preventive and health promotion services) to a higher technological care at the secondary and tertiary level, formal educational efforts need to be directed toward re-tooling health care workers to a home care focus.

6.3 STAFFING CONSIDERATIONS

Staffing configurations are country specific, depending on the numbers and types of health care workers available. Depending on the focus of the home care in the country, there may need to be shifts in the types and numbers of health care workers needed. In addition, shifts in supplies of health care workers require the commitment of resources, including financial resources, and long term planning for the continual training of health care workers. For countries who have had a focus on the primary level of care, a movement to a secondary and tertiary level of care may require shifts from community health workers to nurses. The issue as to whether there should be a multidisciplinary team of health workers or one category of health worker should be at the forefront of decisions around home care delivery and will have to be dealt with, taking into account the local context.

In Brazil, home care is an interdisciplinary program which is lead by physicians and includes nurses, social workers, dieticians, and physiotherapists (Ribeiri, C. A. & Predrosa da Cruz, L., 1998). The role of physicians in Brazil's home care system, *Caring* 17, 12, pp. 40-41).

6.4 VOLUNTEERS

In some localities within some countries, volunteers have arisen from NGOs and church-related groups for either specific kinds of clients or in specific localities. Coordination of volunteer activities is important to prevent duplication of services and to ensure that an adequate scope of care is available in accordance with some minimum standard, or at least to ensure that no harm is done.

In Costa Rica and Nicaragua, brigadistas are local health care workers who act as community volunteers and provide health education to community members. Their focus is on self-care education.

6.5 CULTURAL CHALLENGES

Sensitivity to cultural issues and beliefs is critically important in the delivery of home care. Cultural sensitivity may dictate how home care services are promoted or advertised, how services are initiated for a particular client or community, and how home care is delivered. In addition, decisions about care of the client may be made by a family member or other influential person in the client's life.

7. FINANCING OF HOME CARE

Home care can be a viable strategic alternative or complement to existing services and may assist in controlling health costs in many countries in the Region. Aside from financial considerations, home care can provide a more appropriate site of care or a desired alternative for clients and their families. Again, for those who live in very poor areas, institutional settings provide basic services that are unavailable in the home environment and thus, the institutional settings may be preferred. As well, there are cultural issues relative to the place of the hospital in the society where hospitals hold special status, even among health care providers (Alvarez, A. & Gril, D. 1999). Is home care feasible in a developing country? *Caring*, 18, 2, pp. 22-23.)

The diversity of economic realities and financial challenges in health systems makes dealing with the range of reimbursement alternatives a complex undertaking that requires specific analysis of every area in the Americas. Essentially, consideration of payment for home care services entails defining the organization and systematization of reimbursement where health insurance is involved. In many countries with established home care systems, there is a mix of publicly funded and privately paid for care. Alternatives that include payment based on professional visits, episode, or exacerbation of disease, or on procedures are some of the alternatives currently in place and now being studied. One financing alternative to be considered for this kind of care is prospective payment based on episodes or visits. Prospective payment for home care, although highly complex, is a financing alternative that is being used in the United States.⁽¹⁸⁾

As an example of the complexities of financing, even within the public system, payment for hospital care can be provided through the Ministry of Health, while primary care is provided through the municipality or region. Determination of where home care originates from, who controls the system and how it's paid for are difficult issues to resolve.

Home care is relatively inexpensive to institute because of the relatively low capital expenses required. Unlike hospitals and institutional care sites, there are fewer requirements for buildings and equipment. The majority of expense is related to salaries and travel expenses. Depending on the background of the healthcare providers, additional education may be needed for working in the community and outside the institutional setting.

7.1 COST EFFECTIVENESS

The effectiveness of home care, from both a cost effective strategy as well as a cost benefit strategy, has been evaluated among varying populations with diverse care needs. Thus, an overall statement of the effectiveness of home care is not possible. However, there is scientific evidence that home care is effective for select groups of clients—mothers and infants, low birth weight babies, women with high risk pregnancies, technology dependent children, and clients who have undergone joint replacement surgery,⁽¹⁹⁻²¹⁾ although the evidence is not consistent.⁽²²⁾ For other groups of clients, such as frail elders with high levels of functional dependency, home care may be more costly than nursing home care because of the high levels of needs of such clients.⁽²³⁾ Among other elders with chronic illness, specifically heart failure, there is evidence that nurses with advanced preparation who provide home care can reduce rehospitalization and lead to better overall outcomes.⁽²⁴⁾ Finally, there is insufficient scientific evidence to allow for the determination of cost effectiveness or cost benefit analysis for many groups of home care clients. Thus caution is warranted in assuming a lack of effectiveness or benefit for other specific populations.

In Uruguay, CASMU, a capitated health plan, did a study which showed that home care was one third the cost of hospital care. The distribution of home care costs was: 48% drugs and supplies, 26% salaries, 18% other interventions like oxygen and blood transfusions, and 8% laboratory studies.

In a systematic review of the research literature from Canada, the US and the UK, home visiting by public health nurses was found to have positive outcomes on physical and mental health, health habits and service utilization (Ciliska, D., Hayward, S., Thomas, H., Mitchell, A., Dobbins, M., Underwood, J., Rafael, A., & Martin, E., 1996). A systematic overview of the effectiveness of home visiting as a delivery strategy for public health nursing interventions. *Canadian Journal of Public Health*, 87, 3, 193-198.).

For countries where hospital overcrowding is a problem, home care can provide an alternative to costly hospital stays for selected clients. Some of the clients for whom home care could be a viable alternative includes clients who are in the recovery phase from an acute/illness or injury or exacerbation of a chronic illness (the third level of care). For example, a client recovering from a hip fracture, without additional complications or morbidity, could be discharged home to continue rehabilitative therapy under the guidance of a physiotherapist or a nurse specially trained in such care. For clients with an exacerbation of a chronic illness, such as heart failure, once the client has been judged to be

medically stable, the client could be discharged home with home care nursing for follow up instruction to the client and family on medication management and symptom recognition. With sufficient help at home from family caregivers, such clients could be discharged home with home care follow up, freeing a hospital bed for a client who is more acutely ill.

In addition to countries where hospital overcrowding is a problem, home care can also provide benefits for countries where hospital length of stay has been determined to be excessive. While shortening length of hospital stay is a worldwide phenomenon, there is concern that hospital discharges are occurring without sufficient home follow up by health care professionals. At the same time, it is important that hospital discharge and referral to home care be undertaken in a systematic manner, perhaps using care algorithms to determine which patients should be referred to home care.

Home care can also help in reducing rehospitalization rates or in reducing length of stay for rehospitalizations because there is earlier detection of symptoms and problems that can be addressed in a timely manner. Determining indicators of rehospitalization is complex for home care clients with recent evidence indicating that the development of a new problem is the leading reason for rehospitalization for clients with heart failure.⁽²⁵⁾ A final important aspect of home care effectiveness lies in other important benefits such as a reduction in some aspects of caregiver burden and improved quality of life for clients and families.^(23, 26) These benefits are less tangible and harder to measure but certainly important measures of success for any health service. In addition, home care helps to keep families together and provides an avenue for the empowerment of the family within the health care system.

8. QUALITY AND COST

Home care providers everywhere are grappling with financial issues and are concerned about maintaining high-quality care in changing environments. Striking a balance between maintaining the quality of services and holding down costs is a global problem.

Some suggestions to create or preserve quality home care services at reasonable cost include:

- setting overall program objectives for what home care is intended to achieve
- setting goals for individual clients in collaboration with family members, taking quality and cost effectiveness into account
- the development of methods of measuring quality
- the creation of guidelines and standards
- integration within existing and development of new information systems
- a mechanism for evaluating quality (sometimes referred to as accreditation), which is universally applied and affordable for all home care providers
- measures of client and provider satisfaction
- reporting and accountability to authorities and the public

Two well known accrediting bodies include the Canadian Council on Health Services Accreditation and the U. S. based Joint Commission on the Accreditation of Healthcare Organizations.

More and more individuals, governments and insurance companies are expected to turn to home and community care because it is can be less costly and may preferred over institutional care by the consumers of health care. When addressing the issue of quality and cost, there appear to be two major trends: one, an accelerated demand for home- and community-based care and two, pressure to reduce the cost and payments for health care in many countries.⁽¹¹⁾ In Canada, where the hospital at home system has been tested, hospitalizations have been found to be averted, which resulted in a substantial cost savings (Brazil, K., Bolton, C., Ulrichsen, D., & Knott, C., 1998). Substituting home care for hospitalization: The

role of a quick response service for the elderly. *Journal of Community Health*, 23, 1, pp. 29-43).

9. CHALLENGES FOR THE IMPLEMENTATION OF HOME CARE

Although it is true that the implementation of a home care program can offer many benefits for the health services, clients, and their families, it is nonetheless also true that implementation of programs of this nature can also present major challenges.

Some of these challenges may include:

- 1) The high variability of referral standards stemming from communication and cooperation difficulties among the working teams within an institution or among the different care levels is a critical factor in the operation of a home care program. It is thus essential to design systems that ensure adequate coordination among the different institutional and professional levels.
- 2) The resources necessary for launching a home care program may pose a serious threat to implementing these kinds of programs, unless it is borne in mind that programs of this nature will not produce immediate, but only medium- or long-term savings for the health systems.
- 3) Geographical isolation, which is a hindrance to referral and monitoring of quality of care and associated expenditures.
- 4) The availability of drugs and technology in the home care setting, particularly for isolated or rural areas
- 5) Family expenditures are frequently increased, not only financial but emotional, free time, and time off from work
- 6) The workload and responsibility of the families of clients receiving home care is increased, with much of it borne by women.
- 7) Well thought out, sound policies for the establishment and continuation of home care services are rare.

Awareness of these potential challenges will make it possible to be proactive and thus give these initiatives a better chance of success.

10. CONCLUSIONS

One of the Pan American Health Organization's goals is to offer guidance through technical cooperation on the organization and management of home care systems and services in Latin America and the Caribbean, while promoting the integration of home care as part of the health care delivery system.

For PAHO/WHO to be at the forefront in reforming health care delivery systems we must help countries to review issues with respect to home care delivery systems and note the challenges that caregivers, consumers, the health sector, and policymakers must face in an environment of reform.

PAHO's future objectives for providing technical co-operation for the organization and management of home care as an integral part of the health care system are to:

- provide an international forum for an exchange of views among health authorities, caregivers, and users on ways and means of dealing with key issues around home care.
- incorporate home care information into a framework of factors that can be used for a descriptive comparison.
- facilitate wider participation in the support of present and future activities by PAHO and the national counterparts related to home care systems and services. In other words, to serve as a clearinghouse.
- eventually, to develop standard guidelines with the countries in order to improve and develop home care delivery service.

Countries need to establish health information networks to facilitate the collection and transmission of timely, accurate information for home care and other health sectors. There is also a need to develop an accountability framework for the health system that includes home care and attempts to apply accountability mechanisms to this sector through the development of performance measures and outcome assessments. Eventually, standards and guidelines for the services provided under home care programs and for new classification of workers who are charged with delivering these services should be developed. Approaches will be different, depending on the needs and resources within each country.

Home care is a viable component of the health care system that has yielded encouraging results in terms of improving the quality of life for clients, increasing client and family satisfaction, and

producing better or equal health outcomes for some home care clients compared with hospitalized clients.^(13-14,19-20 22) There is also evidence that home care is efficacious in preventive health care. For selected clients and families, home care is a viable alternative to other sites of care.

The cost-effectiveness of home care programs nevertheless depends on the proper selection of clients and the timing for their admission into home care programs of this nature. The structuring of home care programs, as much as the coordination of these programs with the different levels of health care and the community, is a key element for the success of these initiatives, in terms of health outcomes and cost-effectiveness.

Home care is one of many community-based modalities for countries to consider as they address future health care sector reform. There are other community-based modalities to consider such as adult day care, group homes, infirmaries for the poor elderly, hospice (either institutional or home-based), and other supportive living environments. In some cases, care may exist within a continuum of services where individuals move from level to level as their needs change. As well, community-based services promote the continued involvement of individuals with their families and communities. Integration of community-based services within the general health care system is vital to avoid fragmentation of care or alienation of the client from the family and community.

The pooling of experiences and resources from the various countries contributes strength and insight that is not available from a sole country-by-country examination. This report is a first step and there are a variety of next steps that would be appropriate. In the following section, we make recommendations for both member countries and PAHO that map the future directions on the matter of home care.

11. RECOMMENDATIONS FOR COUNTRIES

The working group provides a series of recommendations for all countries in the Region, recognizing that the specific sociopolitical, economic and cultural contexts will have a great influence on the decisions made within each country. The primary recommendations are:

- The development of and refinement of home care programs should be considered as health care sector reform activities ensue.
- Countries who have no or little home care should be encouraged to consider expansion of the home care programs.
- Countries who have well established home care programs need to be encouraged to continually evaluate the impact of reform measures on client access to care and the impact on clients and families, not just the impact on the financial system.

The following recommendations are made in no order of priority:

- As health sector reform continues, countries should encourage funding schemes, both public and private, that include home care services as part of the basic package of services.
- Quality evaluation activities should go beyond the evaluation of only structure of the organization and process of care, but focus on client outcomes as the most important evaluation measures.
- Integration of activities within all three levels of health care should be encouraged with an emphasis on primary care.
- Each country should endeavor to develop and maintain a list of relevant home care providers and professional home care organizations.
- For some countries, where the health care providers are not familiar with community-based health care, educational programs are needed to re-train and re-orient health care providers. Similarly, for countries where the home care programs are expanding from primary into secondary and tertiary levels of home care, additional training may be needed. Role delineation and competency standards for all home care providers require consideration.

Ministries of Health in some areas now have less direct responsibility for actual provision of health care but remain in the critical role of directing health services. Ministries of Health have a central role in policymaking, the development of quality improvement or quality evaluation, and the integration of home care into the health system. In countries where health system decisions are made on a provincial, regional or local level, a federal role in decisions on regulations and quality activities would help to provide an overall structure for the organization and management of home care. Ministries of Health can also provide guidance as the private sector, either organizationally or through the provisions of health insurance plans, begin the process of developing home care programs.

11.1 RECOMMENDATIONS FOR WHO COLLABORATING CENTERS

The WHO Collaborating Centers can play a valuable role in providing technical assistance and guidance in the development of home care programs. WHO Collaborating Centers can provide network development—putting experts in contact with countries requesting assistance. More specifically, Collaborating Centers can provide training, policy methodologies, and tools to support the development of home care.

11.2 RECOMMENDATIONS FOR PAHO

As a result of our work on home care, our recommendations are that PAHO:

- Encourage creative models of home care organization and financing with efforts made to share success stories across countries that are faced by similar populations and health care systems. Each home care system reviewed and discussed had strengths and weaknesses—there is no gold standard for home care.
- Formulates a policy statement on home care to guide the member countries in this area at the regional level as countries consider health sector reform.
- Encourages and supports the execution of situational analyses and needs assessments, so as to evaluate what exists and what is needed in countries that are developing home care programs.
- Continues to support dialogue and working groups with in-country experts, specialists, policymakers, and decision makers on further development within this area.

- Develops and disseminates methodologies, instruments, and other tools to support home care programs are being developed and implemented.
- Includes a section on home care in Health Sector Reform Initiative for Latin America and the Caribbean and other relevant publications.
- Within the next twelve months, using the pilot study format previously used by PAHO for other projects, develop three or four pilot projects to implement, refine and test models of home care.
- Convenes forums to share experiences of developing home care and the lessons learned between countries.
- Encourages the use of systematic methods of outcome measurement for selected indicators or a minimum set of indicators for the evaluation of home care.
- Encourages collaboration with interested parties, national and international organizations with an interest in home care (nurses, physicians, home care associations and professional organizations).
- Within three years, convenes a working group to evaluate progress in home care development in the Americas and make suggestions for a future course of action.
- Endeavors to develop and maintain a home care database that describes the organization and management of home care with the Region's countries, available on the World Wide Web which includes contact persons.

11.3 COLLABORATION WITHIN PAHO DIVISIONS

We recommend that there be collaboration with other PAHO divisions. There are several divisions within PAHO that we consider critical for involvement because the issues overlap between divisions: Non-Communicable disease program, Women's Health, AIDS, Elders, Human Resources, and Mental Health.

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ANNEX I: AGENDA

WORKGROUP ON THE ORGANIZATION AND MANAGEMENT OF HOME CARE SERVICES IN THE AMERICAS

**WASHINGTON, D.C.
17-19 NOVEMBER 1999**

Wednesday November 17, 1999

Morning

- Introductions
- Overall response to the draft working document
- Initial discussion of country profiles and whether/how to include
- Major topics to be added
- Assignments for major topics to be added

Afternoon

- Section by section review/discussion
- Assignment of sections which need expansion, clarification or explanation

Thursday, November 18, 1999

Morning

- Writing new/revised sections
- Discussion of format for country profiles

Afternoon

- Revision of country profiles
- Continued working on draft document

Friday, November 19, 1999

Morning

- Recommendations for:
 - PAHO collaboration
 - Work within/between countries
 - Other groups/organizations to include
- Defining what are the most urgent needs and tentative solutions to those needs
- Next steps and responsibilities for completion of the document.

ANNEX II: PARTICIPANT LIST

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WASHINGTON, D.C.
17-19 NOVEMBER 1999

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